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Living with Asperger's syndrome - the phenomenon of
“not quite fitting in”

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Declaration

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Abstract

This qualitative study explores the experiences of young adults with Asperger's syndrome and their parents. Using grounded theory methodology, young adults with Asperger syndrome (n=18) aged 18-35 years and parents of young adults with Asperger's syndrome (n=23) were interviewed. Participants represented twenty-five families and a total of 42 face-to-face interviews with young adults and parents. Some interviews were carried out with young adults and parent/s together, others separately. Secondary or other data sources were used in the constant comparison of interview data, this included published personal accounts and notes taken from telephone conversations, meetings and conferences. Theoretical sampling and constant comparative analysis were the processes by which a substantive theory emerged about the phenomenon *not quite fitting in* - a multi-dimensional concept that offers one explanation of the varying experiences of both young adults with Asperger's syndrome and their parents.

The non-obvious nature of Asperger's syndrome was central to the overall experience of *not quite fitting in* for young adults and their parents. Young adults 'looked normal' and had normal levels of intelligence but they behaved in ways that seemed 'socially inept', 'socially awkward', 'inflexible', and 'lacked empathy'. They expressed 'feeling different' from others, and had difficulty identifying a sense of 'self' in relation to others. Parents also described ways in which they did *not quite fit in* to normal expectations of parenting an adult son or daughter. Parents did not regard themselves, nor were they recognised by others, as 'informal carers'. Furthermore their son or daughter did not perceive themselves as being 'cared for'. Nevertheless, the data revealed a considerable amount of 'caring' involved for parents, both psychological (psychological 'watching over', companionship, managing emotions) and practical (providing shelter, food, security, money). Interestingly, this unacknowledged 'caring' was often carried out without the knowledge of young adults, and was both inadvertently and deliberately 'covert' in nature.

Through the process of constant comparative analysis, the phenomenon of *not quite fitting in* was theorised through integrating the findings with other literatures; biographical, empirical and theoretical. Through this process, a symbolic interactionist perspective, derived from the work of G.H Mead (1934) about self and society, emerged as a framework that offered a theoretical explanation for the phenomenon of *not quite fitting in*. The study also reflects on the many ethical and practical dilemmas of undertaking research with this particular group of participants. Finally, the study has implications for practice and further research in relation to health care professionals, such as health visitors, school nurses and family doctors, who are not specialists but who may come into contact with children and adults 'living with Asperger's syndrome', often before a diagnosis has been made. In concluding the study these implications for practice are briefly outlined for the stimulation of further thought, discussion and research.

Chapter one

Introduction

1.1 Introduction

The study is about the experience of *not quite fitting in* as experienced by young adults with Asperger's syndrome and their parents. This introductory chapter will set out the background, aims, terms of reference and rationales for the study, as well as introduce each of the chapters. Finally, the reason for locating the study within a department of nursing studies and its relevance to community health care professionals will be argued, recognising that this is an area that somewhat paradoxically *does not fit in* easily to any of the professional disciplines including nursing, medicine, learning disabilities, mental health, social work, or education.

1.2 Background to the study

The study was conceived, and began, when I was working with a small autistic charity seeking to highlight the local needs of children and adults with Asperger's syndrome. Working with this charity, I was privileged to meet and converse with many individuals and families affected by Asperger's syndrome and attended many support groups, seminars, and conferences focusing on issues relating to Asperger's syndrome. In listening to the difficulties and dilemmas facing many of these families, I found myself wanting to know more about what it means to live with Asperger's syndrome, for those affected and for their families. I chose to look at the lives of young adults because at that time, during the late 1990s, and subsequently, most of the focus of research and service provision seemed to be on children. Adults with Asperger's syndrome and their parents appeared to be a largely forgotten and neglected group, and today, despite growing knowledge and awareness, Wing (2005:201) writes about Asperger's syndrome, "*In the UK there is*

still a dearth of information and knowledge among professionals such as health visitors, social workers and GPs.” Thus the current study was inspired through listening to people living with Asperger’s syndrome, and their parents, and recognising a gap in health care provision and in the research literature.

1.3 Study aim

The purpose of the study was to explore the experiences of young adults with Asperger’s syndrome *and* their parents. The aim was intentionally broad so as to enter the field with as few preconceived notions as possible. However, as Sandolowski (1993a) says, the theories that we carry in our heads inform our research in multiple ways, even if we use them quite unconsciously. I do not claim to have come to this study ‘theory-free’, but I did enter with the desire to be sensitive towards what I did and did not know. Thus I was careful to consider personal assumptions before, during and after interviewing participants. Also, when beginning the study I was relatively unfamiliar with the field and had little understanding of where the concerns of participants might lead the study. This helped me to approach participants without a set agenda and set broad study objectives, which included:

- to develop a sense of the experiences of both young adults and their parents
- to be open to the main concerns of participants and to allow the study focus to be directed by the emerging data
- to account conceptually for the main issues and concerns arising from the data
- to theorise the findings through an integration of theory, research and ‘other’ ways of knowing, that is, anecdotal, philosophical and even fictional writings

- to stimulate areas for discussion and further research, and to add to the growing body of knowledge in this area

1.4 Rationale for grounded theory methodology

Grounded theory is the research strategy chosen for this study. This approach particularly appealed following reading Glaser and Strauss' (1967) classic book 'The Discovery of Grounded Theory'. Having been written in the year of my birth, I was stuck by its apparent relevance today. I was excited by the authors' claims that grounded theory was suited to helping participants in a substantive area by the discovery of participants' problems and through generating a theory 'grounded' in their main concerns. Thus, because 'grounded theories' are drawn from the data, Strauss and Corbin (1998a:12) suggest they are *"likely to offer insight, enhance understanding, and provide a meaningful guide to action"*. Therefore grounded theory was one way to *"capture the complexity of reality (phenomena) we study, [...] to make convincing sense out of it"* (Strauss 1987:10). Grounded theory also offered a systematic, yet flexible, framework that could guide me in the research process. Finally, grounded theory methodology seemed an appropriate way to increase understanding in an area of 'uncharted territory' (Chenitz and Swanson 1986). Hence, this approach seemed appropriate in exploring the lives of young adults living with Asperger's syndrome, and their parents, from their perspectives.

1.5 A 'nursing' study

The study was located academically within a department of nursing studies. However, it could feasibly have been located within a number of different fields

other than nursing. For example, social psychology, medical sociology, education, learning disability or mental health studies, which as mentioned, reflects the *not quite fitting in* status of the topic area. Whilst the study does not describe ‘nursing’ interventions or a client group likely to be familiar to the majority of nurses, as a health visitor, central to my practice and professional thinking are four key principles of health visiting education and practice (CETHV 1977):

1. the search for health needs
2. the stimulation of the awareness of health needs
3. the influence on policies affecting health
4. the facilitation of health enhancing activities

These principles were first described by the then Council for the Education and Training of Health Visitors (CETHV 1977) and later affirmed and reaffirmed to be as relevant as ever to the health visiting profession (Twinn and Cowley 1992; Cowley and Appleton 2000). Thus, mindful of these principles to my area of clinical practice, I considered that a study exploring the experiences of a group of hitherto ‘hidden people’ with likely ‘hidden health needs’ was congruent with the principles of health visiting, in particular with principles ‘search for health needs’ and to ‘stimulate an awareness of these needs’. Given there are few policies or guidelines specific to the care of people with Asperger’s syndrome (Morton-Cooper 2004), the findings may also be helpful in contributing toward influencing policies, as well as facilitating health enhancing activities for people with Asperger’s syndrome and their families. As Cowley and Appleton (2000:16) highlight,

“Health visitors acknowledge a professional responsibility to search for both recognised and unrecognised needs in individuals, families and the wider community.”

In addition, research in nursing traditionally draws from eclectic sources of knowledge, and since from the outset I wanted to conduct the study with an ‘open

mind' and not be constrained by any particular way of thinking about the experiences of the people I was meeting, nursing also provided an environment that could encourage, accommodate and nurture this study. Thus to conduct the study within my own professional sphere of education and professional practice, 'nursing', seemed to be an appropriate and potentially fruitful way to proceed.

Finally, the study findings are relevant to helping nurses and other health care practitioners in contact with people with Asperger's syndrome in primary care, which can also apply to those in acute settings. For to understand some of the issues and problems facing these patients and their families, Morton-Cooper (2004:12) argues,

"The quality and kind of health care people with Asperger's syndrome receive will depend not only on the interpretation of their needs by others close to them, but also on how 'autism-aware' frontline healthcare workers are and attuned they may be to modifying their practice to accommodate communication and sensory problems."

Given the paucity of research by nurses in this area, the study will add knowledge relevant to primary health care and other health professionals. At a time when increasing numbers of children are being diagnosed with autism spectrum disorders (Baird et al 2006), the study seems particularly timely.

1.6 Terms of reference

For clarity and consistency in an area of considerable confusion over the terms used and their definitions, the main terms of reference adopted within the thesis are now defined. This includes understanding how I perceive the controversial relationship between Asperger's syndrome and autism. Furthermore since there are two distinct

but overlapping groups of participants, young adults and parents, this section will indicate how these different participants will be referred to throughout the thesis.

i) Asperger's syndrome and Autism

The term 'Asperger's syndrome' is used here in relation to young adults. All except one young adult participant had received a clinical diagnosis of 'Asperger's syndrome' or 'high functioning autism' by a diagnosing clinician such as a psychiatrist or a psychologist. The parents of the one young man who had not received a clinical diagnosis believed that he had Asperger's syndrome, but had not sought a clinical diagnosis as they could see no benefit to him in doing so. For the purpose of the study, confirming the diagnosis was not considered relevant. It was the perspectives of participants that were important and I had no reason to doubt the parent's perspective in this instance.

'Asperger's syndrome' is the diagnostic term of choice for the study title and is used throughout the thesis to refer to all 'young adults' regardless of their precise diagnosis, for example, two young adults have diagnoses of 'high functioning autism'. Asperger's syndrome is the term used throughout because the majority of participants (23/25 cases) used this term to describe themselves, or their son or daughter. Chapter two discusses the debates, anomalies and history of the terminology used, for example, Asperger's syndrome, high functioning autism, autism, and the autism spectrum. In presenting the stock of knowledge, it is often impossible to separate the wider 'autism' research from that of 'Asperger's syndrome', and thus chapter two integrates the literature around Asperger's syndrome with 'Autism' related literature.

ii) Young adults

‘Young adults’ is used with reference to participants with Asperger’s syndrome rather than ‘young adults with Asperger’s syndrome to aid the flow of writing.

iii) Parents

The term ‘parents’ is used when referring to parent participants, all of whom had an adult son or daughter with Asperger’s syndrome still living with them, and to varying degrees still dependent on them.

iv) Participants

When the term ‘participants’ is written, this refers to all participants, both young adults and parents. When referring a particular group, this will be specified, for example, ‘young adult participants’, ‘young adults’, ‘parent participants’, or ‘parents’.

1.7 Structure of thesis

In chapter two, the stock of knowledge surrounding Asperger’s syndrome is presented. This was not intended to be a traditional literature review, which is regarded as unnecessary and unhelpful within grounded theory methodology (Glaser 1998). Instead the literatures (biographical, research and theoretical) were integrated during the latter stages of analysis to compare and expand the study findings. Thus the existing literature was used to support and inform the study findings rather than direct the study agenda. The body of ‘Asperger’s syndrome’ literature is also helpful to understand how studies carried out in the 1940s (Kanner 1943; Asperger 1944) have influenced current understanding, and some

misconceptions, about people with Asperger's syndrome. Chapter two, therefore, helps 'set the scene' for understanding some of the difficulties experienced by participants in relating to people around them, in participating in the study, and in their perceptions of the diagnosis. Finally, the stock of knowledge set out in chapter two helps to position the findings of the study within the context of what is a fast growing body of literature.

In chapter three, the methods used to conduct the study are presented in detail. This not only gives a step-by-step explanation for how the study was carried out but also, together with the appendices, contributes towards establishing an audit trail in order to establish the credibility of the findings. To support the audit trail, two full interview transcripts, a coding list, and examples of memoing can be found in Appendix 1.

Chapter four identifies and reflects on the many ethical and practical dilemmas encountered throughout the research process. This chapter stands as separate from the methods chapter because there were several important issues that arose for both participants, and for me, as researcher; not least the experience of being a researcher, health visitor and worker in the field. Furthermore, there is a shortage of ethical discourse in the research methods literature about research involving participants with subtle social and communication impairments.

In chapter five, the findings pertaining to young adults are presented. The data source for this chapter came primarily from young adults' interview accounts. However, in places, data from parents' accounts are used to further explain or add meaning to the point being made. In chapter six, parents' accounts are presented,

and the primary data source for the chapter is almost solely parent participants' accounts. This is because young adults' accounts centred wholly on themselves; they had little to say about their parents, and thus did not add meaningfully to the understanding of parents' experiences. Throughout the presentation of findings in chapters five and six, the concepts and categories presented, many of which are interrelated, 'build' upon each other to form the core category *not quite fitting in*. The phenomenon of *not quite fitting in* encompasses a number of dimensions. For young adults this included: 'looking normal', feelings of being 'different', 'alienated' and of 'not belonging'. The phenomenon is also relevant to parents, albeit in differing ways. Parents *did not quite fit in* with normal roles of parenting either able 'adult children' or of 'caring for' disabled 'adult children'. In addition much of what parents did for their adult son or daughter was unacknowledged by themselves, and unrecognised by young adults. Also parents carried out many activities without telling their son or daughter what they were doing, thus the role of parents is described as 'covert caring'.

Having presented the findings the next task was to compare and integrate the findings with other appropriate bodies of literature. The core category *not quite fitting in* led to an exploration of literature surrounding experiences of human difference. This led primarily to classic sources of literature derived from social psychology (Goffman 1959, 1963; Becker 1963; Scheff 1966, 1996). The roots of this literature led back to the concepts found within symbolic interactionism, in particular, Mead's (1934) concept of the 'self' in relation to society. Thus an outline of this key literature is set out in chapter seven to provide a basis for understanding the discussion of findings and conclusions presented in the final chapter.

Chapter eight represents the final step of the study in the ‘theorising’ of findings. This entails interplay between the findings, established theory and supporting research in the field of autism studies. In grounded theory methodology the generation of theory from the data is often considered enough and the thesis could have usefully concluded with the emergent theory, *not quite fitting in*, and the set of interrelated hypotheses to explain what the phenomenon is, how it occurs and its consequences. In this way, the findings chapters (five and six) can stand alone to contribute to a better understanding of young adults with Asperger’s syndrome and also their parents, thus adding new knowledge. However, a further step in grounded theory is the integration of the new theory into the literature by comparisons with appropriate literatures (Glaser and Strauss 1967). In the study the findings are further analysed through the theoretical perspective of symbolic interactionism, identified as relevant through an exploration of the literature in relation to *not quite fitting in* and human difference. The discussion also integrates relevant literature on ‘Asperger’s syndrome’, including biographical, theoretical and research knowledge. Through this process a number of further hypotheses are presented from which conclusions are drawn.

Chapter nine concludes the study by briefly setting out the potential implications from the study for primary health care professionals, and suggestions are put forward for the stimulation of discussion and further research. The thesis ends by returning to the rationale for the study and the belief that support for people with Asperger’s syndrome and their parents begins with trying to gain an understanding of what the world is like from their perspectives.

1.8 Summary

In this introductory chapter, the background to the study, the study aim, rationale for using grounded theory methodology and for locating the study academically within a department of nursing studies have been set out. The main terms of reference are described and the structure of the thesis outlined. The next chapter presents the 'stock of knowledge' in relation to Asperger's syndrome, considered important in understanding where the present study 'sits' in relation to this rapidly growing body of knowledge.

Chapter two

Stock of knowledge: Asperger's syndrome

2.1 Introduction

In this chapter, the stock of knowledge relevant to the understanding of Asperger's syndrome will be presented. In order to position the study within the wider body of knowledge apropos Asperger's syndrome, an overview of the current body of knowledge and the historical development of understanding about Asperger's syndrome will be set out. Relevant 'autism' related literature will be included because much of the literature concerning Asperger's syndrome is embodied within the wider autism spectrum. An overview of the considerable body of knowledge will also be discussed because as a researcher (and reader) it would seem important to understand the prevailing discourse in autism studies, especially since much of this discourse can be applied to the experiences of participants *not quite fitting in* to normal patterns of childhood development, socialisation, and 'self' identity (as discussed at length in chapter eight).

In grounded theory methodology, the use of the traditional literature review in the formulation of the study's research question is advised against (Glaser and Strauss 1967; Glaser 1998) and thus the purpose of this chapter and justification for its existence will be addressed first. This will be followed by a historical documentation of the relevant stock of knowledge, from the 1940's to the current day. The focus of the chapter will then address current debates, including the terminology used, an overview of selected autism research literature, and an examination of the limited research literature based on the subjective experience of living with Asperger's syndrome, or of informally 'caring for' a person with Asperger's syndrome. Finally, a gap in the research knowledge will be identified, which this study contributes towards addressing.

2.2 The place of the literature in grounded theory

In this section the purpose of a 'literature chapter' in relation to the study is explained, with reference to the methodological standpoint of grounded theory. Contrary to orthodox research methods, 'grounded theorists' advise against reviewing the literature prior to commencing the study (Glaser and Strauss 1967; Glaser 1978, 1998). For example, Glaser and Strauss (1967) suggest that doing so can lead to preconceptions that may interfere with the process of 'generating theory' that is 'grounded in the data'. Glaser (1998) argues that not reading the literature beforehand is part of the grounded theory 'empowerment' and a dimension of 'freedom to discovery' and the emergence of concepts, problems and interpretations from the data. Likewise, Strauss and Corbin (1998a) advise that there is no need to review all the literature in the field beforehand since it is impossible to know prior to the investigation what salient issues will emerge. However, in contrast to Glaser's (1998) position that familiarity with the literature can 'block creativity', Strauss and Corbin (1998a) suggest ways in which other literatures may enhance a study, for example, through sensitising the researcher to subtle nuances in the data if used with 'awareness' and in a systematic way. All these authors (Glaser and Strauss 1967; Glaser 1998; Strauss and Corbin 1998a) agree that returning to the literature in the late stages of the research having worked out most of the theoretical framework, other literatures; including research and existing theories, can be used to confirm findings or to extend or refine knowledge in the field.

Within the context of the present study, in the early stages I had little knowledge of the area under study, and therefore entered the field with few 'a priori assumptions' of what I might find. Knowledge of the literature surrounding Asperger's syndrome was accumulated throughout the course of the study, and this chapter presents the

stock of knowledge related to Asperger's syndrome, from the historical underpinnings to current day knowledge. Thus, this chapter is an amalgamation of knowledge gained during the study and from returning to the literature in the final stages of the analysis, rather than a traditional literature review carried out prior to the study design. The purpose of the chapter is to 'set the scene' for the context of the study, and to provide a backdrop from which to understand the position of the findings within what is a rapidly growing body of knowledge.

2.3 Asperger's syndrome – the historical context

Although the term 'Asperger's syndrome' is relatively new, the disability was first systematically described, under a different name, in the 1940s. The historical context has relevance to the understanding of current thinking about Asperger's syndrome, and thus a historical overview of the literature surrounding Asperger's syndrome is outlined. The most significant of the early work about Asperger's syndrome is that by Austrian paediatrician, Hans Asperger. '*Autistic psychopathy in childhood*' was the title of Asperger's pioneering paper published in German in 1944. However, his work remained in relative obscurity until it became more widely disseminated when translated into English by Frith in 1991. In his paper Asperger (1944) describes young people with autistic psychopathy, who today would be referred to as children with 'Asperger's syndrome'. Asperger's choice of the word 'autistic' (a word derived from the Greek word 'autos' meaning self-orientated) was derived from previous use within psychiatry of the term 'autism' to describe how in people with schizophrenia there may be a "*shutting off of relations between self and the outside world*" (Asperger 1944:139). The children described

by Asperger in the 1940's resonate with descriptions of today's children diagnosed with Asperger's syndrome, for example, Asperger (1944:37) states,

"They have in common a fundamental disturbance which manifests itself in their physical appearance, expressive functions, and indeed, their whole behaviour. This disturbance results in severe and characteristic difficulties of social integration".

Asperger's paper (1944) reports his doctoral thesis, in which he describes in detail four boys. In doing so Asperger acknowledges each child's uniqueness and highlights their individual differences. However, he also writes, *"those who know such children never cease to be surprised at the striking coincidences of detail"* (Asperger 1944:67). The key similarities he noted are summarised below:

i) A lifelong condition

Asperger found characteristic features to be noticeable by the second year of life, remaining unmistakable and constant throughout whole life. However, he regarded that as intelligence and personality develop certain features predominate or recede so that the presenting problems change considerably.

ii) Physical appearance and expressive characteristics

Asperger saw that these children could be almost aristocratic in appearance. He stated that their faces displayed an early thoughtfulness and *"the furrowed brow betrays the introspective worrier"* (Asperger 1944:68). Furthermore, there are peculiarities of eye gaze as they rarely fix on people but appear distant or tuned inward. This is described as most marked when in conversation,

“Glance does not meet glance as it does when unity of conversational contact is established [...] a large part of social contact is conducted through eye gaze but such relationships are of no interest to the autistic child” (Asperger 1944:39).

iii) Lack of “contact-creating expressive functions” (Asperger 1944:70)

Asperger identified a lack of appreciation of tone, intonation, volume and flow of speech to impart the complex and often hidden meanings of language. Whilst there are many differing expressions of these language abnormalities, he regarded them to all have one thing in common,

“The language feels unnatural, often like a caricature, which provokes ridicule in the naïve listener. One other thing autistic language is not directed to the addressee but is often spoken as if into empty space” (Asperger 1944:70).

iv) Autistic intelligence

This is the presence of special abilities and unusual ways of seeing and conceptualising the internal and external environment. For example, this may lead to creative language, often expressed through bizarre words or phrases; to unusual interests or the collection of particular objects; to a preoccupation towards the functions of their own body; or a surprising sensitivity to aspects of others or the environment that most people would take for granted. This intense, conscious interaction with the whole environment stands in contrast with the ordinary child’s ability to *“instinctively swim with the tide”* (Asperger 1944:74).

v) Behaviour in the social group

Asperger regarded the fundamental limitation of social relationships and behaviour in social groups, as the clearest sign of the condition and the source of conflicts from earliest childhood. These conflicts occur especially within

the family unit, they often appear isolated, and common descriptions include, *“It is as if he were alone in the world [...] he dwells among people as a stranger [...] he is like an alien”* (Asperger 1944:78). They are egocentric in the extreme, following their own wishes, interests and spontaneous impulses. They lack respect for the other person and treat everyone as an equal, speaking with a natural self-confidence. Their lack of respect in disobedience is obvious but they do not show deliberate acts of cheek, rather they have a genuine defect in their understanding of the other person. While they may appear aloof and uninterested in others *“they are capable of strong feelings ... [and] undoubted emotional attachments to animals and particular children”* (Asperger 1944: 83)

vi) ‘Drive and affect’ (Asperger 1944)

Asperger described how the children he presented lacked harmony between ‘affect’ and ‘intellect’. While intellect may be above average, he noted drives and instincts are often severely disturbed, as shown in the failure of instinctive situational adaptation when faced with the practical demands of ordinary life. He recognised the children displayed differences in emotional thought and expressions, which were extremely complicated,

This cannot be understood simply in terms of the concept ‘poverty of emotion’. Rather, what characterises these children is a qualitative difference, a disharmony in emotion and disposition. They are full of surprising contradictions which makes social adaptation extremely hard to achieve’ (Asperger 1944:83).

In noting the above characteristics, Asperger sought to increase awareness of the syndrome, as he believed that these individuals were likely to suffer from ‘tragic misunderstanding’ and consequent maltreatment by others. Remarkably, his

description of 'autistic psychopathy' has much in common with the account of 'early infantile autism' described quite independently by Leo Kanner (1943) only a year prior to Asperger's (1944) paper. Like Asperger (1944), Kanner (1943) describes a group of children with a puzzling combination of symptoms – for Kanner this included an obsessive desire for sameness, echolalia, lack of social responsiveness, oversensitivity to stimuli and restricted interests, combined with a good memory and seemingly good cognitive potential. Kanner's (1943) paper was the first description of 'Autism' as a disorder and was astonishingly similar to that of Asperger's (1944) paper. Both men described children with a poverty of social interaction, failure of communication and the development of special interests, but whereas Asperger described, older, more able children, Kanner's children tended to be much younger and most were more extreme in their distance from reality, for example, the majority were described as 'mute and aloof' (Kanner 1943). Asperger's 'boys' were less obviously in their own world but they did share the defining feature of an inability to make connections with people at varying levels of severity and of various forms (Wing 1991). Although both were Austrian physicians, Kanner lived and worked in the USA publishing his work in English, whereas Asperger remained in Austria and his work was published in German remaining relatively obscure. It was Kanner's (1943) work that became well known and subsequently dominated the prevailing view of autism until the 1980's. Hence, the popular notion of autism as the 'silent and aloof child locked into a world of its own' (Wing 1986).

It was not until 1981, a year after Asperger's death, that his work achieved international recognition when a British child psychiatrist, Lorna Wing, published a detailed account of 34 cases similar to those described by Asperger (Wing 1981).

Frith's (1991) publication of Asperger's (1944) paper translated into English made his original work more widely available, although Wing (1986) points out that long before her 1981 publication, Asperger's work had been introduced to English readers by Van Krevelen (1971) whose paper argued for the separation of Asperger's concept of 'autistic psychopathy' from Kanner's autism. Like Van Krevlan (1971), Wolff and Barlow (1979) also argued that Asperger's 'autistic psychopathy' was different from Kanner's autism and suggested that it should be classified as 'schizoid personality disorder' (a point of view later partially reconsidered by Wolff, 1995). Wing (1981) published her account in response to this, presenting her evidence for regarding 'Asperger's syndrome', together with 'Kanner's syndrome' as component parts of an autistic spectrum characterised by absence or impairment of the development of social interaction, social communication and imagination. In addition, Wing (1981) introduced the term '*Asperger's syndrome*' as a more acceptable alternative to Asperger's then outdated term '*autistic psychopathy*'. Wing (1986) argues that the introduction of the term Asperger's syndrome not only gave publicity to Asperger's work but also countered the popular view of a child with autism as agile, aloof and indifferent to others with little or no speech and no eye contact. Wing (1986, 2005) states her regret at the need for the introduction of more terminological confusion into the field of autism, but remains convinced that the introduction of the term Asperger's syndrome was of help to many families who previously believed they were alone in their problems. For example, Wing (1986:515) says,

"Many find it hard to accept that this diagnosis can be applied to an adult who is ill-coordinated and who, among other eccentricities, fixes them with a gaze as compelling as that of the Ancient Mariner and delivers a monologue on the movements of the planets. Parents and professional workers tend to be more responsive if told that the person has an interesting condition called Asperger's syndrome".

Wing's (1986, 2005) justification for the introduction and continued use of the term 'Asperger's syndrome' regardless of her belief that this condition is an integral form of autism, highlights the difficulties faced by families and clinicians today as the terminology remains confusing and a number of terms are used interchangeably. For example, Kanner's autism, Asperger's syndrome, autism spectrum conditions, autistic spectrum disorder, high functioning autism, mild autism, mild Asperger's, pervasive developmental disorder, semantic pragmatic disorder, schizoid personality disorder. However, in discussing this debate, Frith (2004) maintains that even amidst the prevailing view of an autism continuum, it does not follow that the term Asperger's syndrome should be abandoned. She argues on pragmatic grounds that there is a need to differentiate verbally able children from those who have severe problems with language and show other evidence of learning disability. Furthermore, Frith (2004) also believes that the term has contributed significantly to an increase in the awareness in the general public and *"helped ordinary people to understand what might be the matter with the strange person with narrow obsessive interests and social ineptness"* (p675).

This overview of the historical discovery and development of understanding about 'Asperger's syndrome' demonstrates both the consistency over time of Asperger and Kanner's observations, as well as the changing perceptions of how Asperger's syndrome should be classified, a point that will now be discussed further.

2.4 Asperger's syndrome – the current debate

Whilst there appears to be growing consensus amongst researchers in the field of autism that Asperger's syndrome belongs to an autism spectrum (Wing 1981,

Medical Research Council 2001; Frith 2004; Baird et al 2006), the two major systems of classification: *International Classification of Diseases - 10th Revision* (ICD-10) (World Health Organisation 1993) and the *Diagnostic and Statistical Manual of Mental Disorders – 4th Edition* (DSM-IV) (American Psychiatric Association 1994) classify Asperger's syndrome as a *distinct* category from autism. Both these systems of classification emphasise that a person who meets the criteria of autism cannot be given the diagnosis of Asperger's syndrome. This excludes the concept of Asperger's syndrome as a continuum to the autism spectrum and contradicts the increasing appreciation that children who meet the criteria of autism in early childhood can move along the spectrum developing characteristics more akin to the picture of Asperger's syndrome, in that they become more verbal and seek to interact rather than remaining passive and aloof (Gilchrist et al 2001; Medical Research Council 2001). This distinction between high functioning autism and Asperger's syndrome currently made by ICD-10 and DSM IV on the basis of early language delay in autism is highly contentious, because, as Wing (1996) points out, many adolescents who have the behaviour Asperger described, were late speakers and there may be many reasons behind delayed speech development making this an arbitrary division. In their review of autism research, the Medical Research Council (2001) highlight the lack of research to validate these subdivisions at cognitive, neurobiological or aetiological levels, and Gilchrist et al (2001) assert the view that these groups of children seem far more alike than different when followed through to adolescence. Some who accept that autism extends beyond its narrowly defined diagnostic boundaries also urge caution when referring to an autism spectrum. For example, Fombonne (1999:124) states,

“It is still very unclear how this enlarged phenotype of autism should be defined and measured [...] the concept of autistic spectrum disorders provides a convenient way to encapsulate all disorders thought to be linked to autism [...] the validity of variants of autism (i.e. Asperger’s syndrome) and their relationships with narrowly defined autism, remain to be established using data independent from their symptomatic definition, such as outcome, family, psychological, biological or response to treatment data” .

The question of whether Asperger’s syndrome is or should be a distinct or continuous category of autism continues to be debated amongst ‘experts’, researchers, parents and individuals with Asperger’s syndrome alike (for example, see Exley 1998; Fombonne 1999; Mayes et al 2001; Kasari and Rotheram-Fuller 2005) and there is still no agreement on the diagnostic criteria for Asperger’s syndrome (Rutter 2005). Furthermore, amongst some experts in the field of autism studies there is a suggestion that autism and Asperger’s syndrome lie on a continuum, not just with each other, but also with normality (Asperger 1944; Wing 1981, 1996; Frith 1991; Baron-Cohen 1995, 2003; Happé, Briskman and Frith 2001; Wakabayashi et al 2006) whereby there are some individuals within the general population thought to have degrees of ‘autistic traits’ or, as having the so called ‘enlarged autism phenotype’ (Fombonne 1999; 2005). This illustrates the difficulties that abound for both researchers and clinicians in defining and diagnosing Asperger’s syndrome. However, what seems to be important is the acknowledgement that there is no single, uniform presenting picture of Asperger’s syndrome. Asperger (1944) himself stressed no two people with Asperger’s syndrome are the same and the expression and effects will be different for every person and family. Sacks (1995:238) also highlights this point: *“there is always an intricate and potentially creative interaction between the characteristics of autism and the other qualities of the individual and their environment”*. Whilst this may

seem obvious, it seems important to emphasise both the differences and variation in people with Asperger's syndrome, which exist as with all human beings, as well as the 'remarkable' similarities of the underlying condition affecting communication, socialisation and adaptability.

Thus, Asperger's syndrome is described as a developmental condition of which individuals share core impairments, but with many and varied expressions and levels of ability and disability. With the current absence of any biological marker for autism spectrum conditions, diagnosis is made solely on the basis of developmental and behavioural characteristics. Couple this with the discrepancies and differences in the diagnostic manuals (World Health Organisation 1993; American Psychiatric Association 1994) it is unsurprising that clinicians vary in their diagnostic conclusions and use a variety of labels to describe Asperger's syndrome. There is even disparity in how the syndrome is referenced in the literature. Within the two major classification systems the World Health Organisation (1993) use the term 'Asperger's Syndrome' whilst the American Psychiatric Association (1994) use 'Asperger's Disorder'. Lorna Wing, who coined the term, originally spelt it 'Asperger syndrome' (Wing 1981) and later (Wing 1986, 1996) adds 's' for 'Asperger's syndrome'. To add to the confusion The National Autistic Society prefer to use a capital 'S' for 'Syndrome' thus they write, 'Asperger Syndrome'. Furthermore, Frith (2004) points out the uncertainty as to how to pronounce the name saying "*The 'g' in Asperger is pronounced as in 'get' and not as in 'gem'*". For the purpose of consistency I use the term 'Asperger's syndrome' throughout the thesis.

To sum up this section, Asperger's syndrome is widely believed to belong to a spectrum of autism conditions with studies dating back at least to the 1940's. However, it is only in the past 20 years that Asperger's syndrome and the wider spectrum of autism has gained greater professional and public awareness. The boundaries of autism and Asperger's syndrome to date remain unclear and unfixed making precise definitions difficult. However, as Asperger (1944) himself remarked, there does appear to be some 'striking coincidences of detail' in children with Asperger's syndrome, making this group of people particularly intriguing but complex to try to understand. It is these overall similarities that have led to the development of theories of autism spectrum conditions that will now be discussed.

2.5 Overview of current research literature

In this section research literature selected for its relevance to the findings of the current study is considered; this includes some of the major theories of autism and Asperger's syndrome, aetiology, prevalence, and co-morbidity with other conditions. Because the research literature relating to Asperger's syndrome is often carried out with reference to the wider group of 'autism spectrum conditions', it cannot be neatly separated from 'autism'. Indeed, since the notion of a unified spectrum across severity and ability levels is strongly supported, it is likely that it is not always appropriate, or possible, to fully differentiate them, therefore the research considered here relates to the broad body of 'autism spectrum' research and understanding.

2.5.1 Theories of Autism and Asperger's syndrome

There are several theories of Autism/Asperger's syndrome and this is not an exhaustive look at all such theories but rather a selective discussion of those that may be relevant to the study being reported. The most prominent of 'social-psychological' theories are considered: the triad of impairments, the theory of mindblindness, and weak central coherence. In addition, two new and related theories of autism: 'hyper-systemising' and 'assortative mating' (Baron-Cohen 2006), are also discussed in brief, although as yet there is limited research to substantiate these new theories.

i) The triad of impairments

Wing and Gould (1979) introduced the notion of the 'triad of impairments' to help raise understanding of autism and to aid diagnosis. The 'triad' describes three areas of impairment: social interaction, communication and imagination. It is this theoretical framework that forms the basis for the diagnostic criteria in both the ICD-10 (World Health Organisation 1993) and the DSM-IV (American Psychiatric Association 1994).

The concept of the triad of social impairments was developed following Wing and Gould's (1979) now classic population study of children from Camberwell, South East London. The aim of the study was to examine the range of clinical phenomena in children to see if 'syndromes' named in the literature could be identified and separated from each other. The children selected were less than fifteen years old and were followed up into adolescence or early adult life. The results showed that children could be divided into two main groups: children who were normally sociable in the light of their mental ages and children whose social interaction was

impaired and would have been abnormal for any mental age. The latter group included all those with autistic features covering intelligence ranges from profoundly retarded to normal. Social impairment was found to be closely associated with impairment of two-way communications and impairment of the development of imaginative activities; especially those related to social understanding. Furthermore, when these problems were present the pattern of activities, instead of being flexible and creative, was rigid, repetitive and stereotyped.

A major limitation of this study, identified by Wing (1993), is that the sample population was drawn solely from children attending special schools or classes. Thus any child with Asperger's syndrome attending normal school and not receiving special educational help would not have been identified. Since the study was carried out in 1979 prior to current knowledge of Asperger's syndrome, they inevitably missed a very large number of children with Asperger's syndrome educated within mainstream schools. Nevertheless, Wing and Gould (1979) did find many children who had the 'triad of impairments' but who did not precisely 'fit' Kanner's descriptions of his syndrome, and they describe an overlap with learning disabilities shading 'into eccentric normality'. This work clearly defined the beginning of a life's work for these authors, led to Wing's discovery of Asperger's (1944) original paper and contributed to her commitment to developing an understanding of children and adults across the autism spectrum regardless of their intellectual ability.

It was from the Camberwell study that Wing and Gould (1979) first introduced the concept of an autism spectrum and interestingly, whilst debates abound about the

term 'Asperger's syndrome' and its continuity or discontinuity with the autism spectrum, the concept of a 'triad of social impairments' persists as the essential feature that distinguishes autism from other developmental conditions and appears to be largely unquestioned. This theoretical framework has thus far stood the test of time, informing diagnostic criteria (American Psychiatric Association 1994; World Health Organisation 1993), as well as being employed by researchers wishing to define their sample populations as belonging to the autism spectrum. Thus the triad of impairments maintains a prominent and important role in the theoretical understanding of the autism spectrum, including Asperger's syndrome. The next two theories originated from the field of neuro-psychology and help to explain the characteristic profiles of people with Asperger's syndrome and why they have difficulties associated with the three areas identified in the triad of impairments.

ii) Weak central coherence

'Central coherence' refers to the everyday tendency to put information together to extract higher-level meaning, for example, to understand the gist of a story rather than its details or exact words (Frith 1989). Frith (1989) developed the theory of 'weak central coherence' in autism to refer to impairments in this process of integrating local information into global meaning. Evidence for 'weak central coherence' in people with autism spectrum conditions has been collected using experimental techniques (Shah and Frith 1993; Happé 1997; Happé, Briskman and Frith 2001) and appears helpful in explaining the tendency of people with Asperger's syndrome to focus on particular features of the environment at the expense of the 'bigger picture'. For example, Shah and Frith (1993) found that individuals with an autism spectrum condition show highly superior performance on

picture tests that required participants to pick out hidden figures. Thus, as well as being a perceived weakness, Shah and Frith (1993) also demonstrate advantages with this cognitive style. A more recent study using experimental psychological (Happé, Briskman and Frith 2001) found 'weak central coherence' to be present in fathers, with normal or superior intelligence, of boys with autism spectrum conditions, which they say supports both the belief of genetic factors in autism, and the notion of a 'broader phenotype shading into normality'. The Medical Research Council (2001) suggests that this theory may also help explain the uneven profile of abilities and disabilities in people with autism spectrum conditions since they often excel at noticing and recalling detailed information, possibly at the expense of processing global information. However, it remains unclear as to what might underlie weak central coherence and alternative explanations have been put forward for these strengths and weaknesses including 'hyper-systemising' (Baron-Cohen 2006) and a reduced ability to generalise (Fisher 2002; Baron-Cohen 2006).

iii) 'Mindblindness'

This highly influential and much studied theory has developed from the neuropsychological 'theory of mind', which refers to the 'everyday ability to attribute mental states' (thoughts, beliefs, desires) in others in order to predict behaviour (Baron-Cohen, Leslie and Frith 1985; Happé 1994; Baron-Cohen 1995). 'Mindblindness', then, refers to the 'inability to infer what others may be thinking, feeling or about to do' (Baron-Cohen 1995). First identified through experimental tests of mental state attribution in children with Kanner's autism (Baron-Cohen, Leslie and Frith 1985), this now seminal paper proposed that deficits seen in autism of 'socialisation, communication and pretend play' could be the result of a 'failure to develop an understanding of others' mental states'. In other words, the

difficulties experienced in the area of the ‘triad of social impairments’ can be explained by the inability to understand what others may be thinking or feeling, and being unable to predict others’ actions. In relation to the consequences of mindblindness, Fisher (2002) points out that a lack of understanding of others’ minds will lead to the individual not seeking to share attention or enjoyment with others. This links to Wing’s (1996:44-45) belief that,

“The pleasures of creative imagination in childhood are denied to autistic people and so are the rewards in adult life. They have limited understanding of other people’s emotions, so find it hard to share happiness or sorrow”.

In addition to evidence supporting ‘mindblindness’ in children, Baron-Cohen et al (1997) also report observing similar deficits in adults with high functioning autism and Asperger’s syndrome. Thus the concept of ‘mindblindness’ provides an interesting theory to help explain why young adults with Asperger’s syndrome appear to have difficulty understanding other people’s thoughts and feelings, and hence, their lack of empathy, as first noted by Asperger (1944). However, there are aspects of autism that ‘theory of mind’ and ‘mindblindness’ cannot account for, such as, ‘islets of ability’ and other cognitive strengths such as enhanced perceptual functioning and it is also not clear whether mindblindness is specific only to, or universal to, children with autism (Fisher 2002).

iv) ‘Hyper-systemising’ and ‘assortative mating’

Baron-Cohen (2006) has recently proposed two related theories, whereby, Baron-Cohen (2006) argues that the human brain engages in ‘empathising’ and ‘systemising’. The empathising system allows for uncertainty and prediction in the face of otherwise unpredictable agents, in other words, allows us to understand the feelings, behaviour and motives of others. Systemising is the search for structure

and rules (patterns, rules, regularities, periodicity), which involves the 'identification of laws to predict that event x will occur with probability p'. Some systems, says Baron-Cohen (2006) are 100% lawful, for example, an electrical light switch, or a mathematical formula, whereas a computer might be an example of a 90% lawful system. However, the social world may only be 10% lawful, thus systemising is not very helpful in predicting the social world. Baron-Cohen (2006) describes a number of differing levels of systemisation, but essentially he suggests that people with Asperger's syndrome tend to be above average in systemisation, and the higher the level of systemising, the less able they are to generalise. He describes this as the 'exact mind' that shows superior attention to detail but a poor understanding of the whole (as described in weak central coherence). Baron-Cohen (2006) concludes that many with Asperger's syndrome are 'hyper-systemisers' that whilst disabling in the social world, can lead to talents in areas that are 'systemisable'. He cautions that many on the autism spectrum never move beyond massive collection of facts and observations (lists of trains and their departure times), but for those who go beyond this to identify a law or a pattern in the data, this can constitute 'original insight'. Thus says Baron-Cohen (2006:4), *"In this sense, it is likely that the genes for increased systemising have made remarkable contributions to human history"*.

Finally, in relation to hyper-systemising, Baron-Cohen (2006) also puts forward the theory of 'assortative mating'. He suggests that there is evidence that autism could be the genetic result of having two high 'systemisers' as parents, highlighting a previous study of his demonstrating that fathers and grandfathers of children with an autism spectrum condition are twice as likely to work in the systemising occupation of engineering, compared to men in the general population (Baron-

Cohen et al 1997). However, in presenting this new theory Baron-Cohen (2006) recognises that it is unlikely to account fully for the current high rates of the 'autism spectrum' and further research in this area is needed. With reference to the different theories of autism, Bailey, Phillips and Rutter (1996) criticise research and theoretical perspectives that focus exclusively on one aspect of the condition. They refer to autism as a 'syndrome' that 'clusters together', and thus they call for an integration of perspectives within autism and across the different levels of research in order to gain an understanding of both the causal mechanisms leading to autism and to the abnormal processes underlying its clinical features. However, not only has the theory of mindblindness been highly influential in accounting for the many difficulties seen in autism spectrum conditions, it also has practical use through the development of early screening tools such as the Checklist for Autism And Toddlers (CHAT) (Baird et al 2000; Charman et al 2001). Furthermore, the theory has led to the search for areas of brain impairment (Happé, Briskman and Frith 2001; Courchesne, Redcay and Kennedy 2004) as well as extensive studies into the genetic basis and implications of autism spectrum conditions (Gillberg and Coleman 2000; Baron-Cohen 2003; Baron-Cohen 2006). Thus, whilst many questions remain, it would appear that the extensive research in this area by Simon Baron-Cohen, Tony Charman, Francesca Happé, Christopher Gillberg and colleagues could no longer be criticised for focusing exclusively on one aspect of the condition.

2.5.2 Aetiology, prevalence, and co-morbidity with other conditions

This section will consider frequently asked questions in relation to Asperger's syndrome, the underlying cause, occurrence, and whether or not it is linked to other conditions.

i) Aetiology

Research has established autism spectrum conditions as a neuro-developmental disorder of unknown cause (Medical Research Council 2001). However, in 1950's Bettelheim (1955) suggested that children became autistic as a result of an unloving environment, which he termed the 'refrigerator mother'. This idea was highly influential at the time in forming professionals' attitudes and treatment of autism, and 'blaming parents' can still pervade professionals' views of parents in relation to their ill behaved child (Jordan 2001).

In recent years, the biological basis for autism has been widely accepted (Gillberg and Coleman 2000). According to the Medical Research Council's review (2001) the current thinking is that several genes may interact to create susceptibility to autism spectrum conditions, but whether environmental factors interact with genetic susceptibility is as yet unclear. There seems to be a strong gender bias with autism spectrum conditions affecting more males than females with the ratio ranging from around 4.1:1 (Wing 1981) to 10.3:1 (Howlin and Moore 1997). Wing (1981) speculates that this pattern reflects greater male susceptibility and a requirement for more severe brain impairment in girls before they express the autism phenotype. The Medical Research Council (2001) also suggest that autism spectrum conditions may be harder to recognise in females using current diagnostic criteria that may identify abnormal behaviours for men more successfully than for women. In addition there appears to be no evidence to suggest a social class or ethnic grouping gradient in the prevalence of the autism spectrum (Medical Research Council 2001; Wakabayashi et al 2006).

ii) Prevalence

‘Prevalence’ measures the number of individuals with a condition at a point in time or over a defined period; in contrast ‘incidence’ measures the development of ‘new’ cases, usually only studied for disorders of clear onset (Medical Research Council 2001). The diagnostic controversies, differences of ‘age of recognition’ as opposed ‘to age of onset’, and the relative newness of the diagnosis of Asperger’s syndrome mean that measuring incidence is problematic (Medical Research Council 2001). Rutter (2005:4) concludes: *“It is not possible to derive a precise figure for the current true incidence of ASD [autistic spectrum disorders], because of uncertainty over the boundaries of the syndrome”*.

Nevertheless, a number of studies have attempted to identify the prevalence of autism spectrum conditions (Lotter 1966; Wing and Gould 1979; Ehlers and Gillberg 1993; Chakrabarti and Fombonne 2001; Rutter 2005; Baird et al 2006). The most recent of which hit UK headline news by reporting a prevalence rate of ‘all’ autism spectrum conditions of 116.1 per 10,000, constituting 1% of the child population (Baird et al 2006). The study by Baird et al (2006) reports a total population cohort of 56,946 children aged 9-10 years. They screened all with a current clinical diagnosis of autism spectrum conditions (n=255) and those judged to be at risk for an undetected case (n=1515). They differentiate between ‘childhood autism’ (38.9 per 10,000) and ‘other autism spectrum conditions’ (77.2 per 10,000), but did not differentiate ‘Asperger’s syndrome’ from ‘other autism spectrum disorders’. The classification system used gives rise to questions over the specified diagnostic boundaries, which suggests they incorporated a ‘broader phenotype’ or wider diagnostic boundaries than other recent prevalence studies showing lower rates. In addition, whilst they appear to have a large population

study, they did not screen all 56,946 children. Rather they screened only those with a 'significant developmental or *language disorder*', as well as those known to be receiving 'substantial additional support' in school. Thus the actual sample was not as large as it may at first appear. In addition, they may also have 'missed' cases amongst more able, more passive, or home educated children, for whom difficulties are less obvious. Most disappointingly, but like the other prevalence studies, these authors do not discuss the ethical considerations of identifying individuals not previously considered affected and for whom there may be no, or few, services or treatment available. The Medical Research Council (2001) did raise these considerations in their recommendations for future research and service provision, but thus far their counsel appears unheeded in the research literature.

Previous population studies have, with a few exceptions, been small scale investigations also carried out with child populations. The first large scale study was undertaken by Ehlers and Gillberg (1993), and carried out in an outer Göteborg borough, Sweden. They used a screening instrument with all children from seven to sixteen years old (target population: 1519 children) to identify those children who potentially had 'Asperger's syndrome' and then undertook a full diagnostic assessment of these children. The criteria used did not exclude those with early language delay leading some to criticise it as 'over-inclusive' (Fombonne 1999), nevertheless even when language delay was taken into account, prevalence rates were 3 per 1000 (Ehlers and Gillberg 1993). Like Wing and Gould's (1979) earlier small population study, Ehlers and Gillberg's study (1993) suggests that such children may be extreme examples of a larger group of children with disorders of social development, which may account for Baird et al's (2006) much higher prevalence rate. Another population study by Chakrabarti and Fombonne (2001)

screened 15 500 children in the UK aged 2½ to 6½ years of age. On the basis of the screening, 576 children were subsequently assessed in depth by a developmental paediatrician and multidisciplinary team. From these children 103 were assessed using an autism diagnostic instrument (Autism Diagnostic Interview). On the basis of this instrument 26 children met the standard for classic autism and nearly three times that number (n=71) met the wider criteria for autism spectrum condition (including Asperger's syndrome). Thus they found the prevalence for classic autism was 16.8 per 10,000 whilst the prevalence of autism spectrum conditions other than classic autism was 45.8 with a total prevalence rate of 62.6 per 10,000 or around 6 per 1000, double that of Ehlers and Gillberg's (1993) earlier study, but still considerably lower than Baird et al's (2006) finding of 116.1 per 10,000. In contrast, the first autism prevalence study by Lotter (1966) found 4.5 children in 10,000 (0.45 in 1000) had autism. Thus it can be seen that over time prevalence rates have increased and appear to continue to do so. However, questions remain over whether or not this represents a real increase or whether this is simply related to greater awareness, better ascertainment, and a broadening of diagnostic criteria to include children who do not meet the strict criteria for autism, often referred to as having Asperger's syndrome, or the 'broader autism phenotype'. Whichever prevalence rate is preferred, it is becoming clearer that, as argued by Gillberg and Wing (1999), autism spectrum conditions should no longer be conceptualised as 'extremely rare'.

iii) Co-morbidity with other clinical conditions

The problems with prevalence studies have also led to a lack of conclusive evidence about the degree of co-morbidity of autism spectrum conditions with other medical

conditions, and considerable controversy exists in this area. Gillberg and Coleman (1996), Fombonne (1999), Gillberg and Billstedt (2000) and Ghaziuddin (2002) have all carried out systematic literature reviews to examine the co-existence and prevalence with autism and Asperger's syndrome of a wide range of medical and psychiatric conditions. Associated medical conditions found include epilepsy, cerebral palsy, fragile X, tuberous sclerosis, sensory impairments, Down's syndrome, neurofibromatosis, congenital rubella and phenylketonuria, with epilepsy and cerebral palsy being the most prevalent. Whilst the reviews clearly suggest links, the reports are unable to conclude whether these are coincidental or whether they are associated.

Nevertheless, links between affective conditions and Asperger's syndrome have long been suggested (Wing 1981, 1996; Tantum 2000; Ghaziuddin 2005). The most commonly associated conditions being: Attention Deficit Hyperactivity Disorder (ADHD), Tourette's syndrome, obsessive compulsive conditions, depression, eating disorders, abnormal responses to sensory stimuli, abnormal sleep patterns, aggression and self injury (Gillberg and Billstedt 2000). It is widely believed that children and adults with Asperger's syndrome are at higher risk of mental health problems including psychiatric disorder (Wing 1981; Howlin 2000; Ghaziuddin 2002, 2005) but there is little systematic research into these difficulties. The main associated psychiatric diagnosis appears to be depression (Wing 1991; Ghaziuddin and Greden 1998; Ghaziuddin 2002, 2005) with speculation that the apparently high rates of depression may reflect the characteristics of the syndrome itself and its neurobiological aetiology. For example, Gillberg (1991) found that first degree relatives of individuals with Asperger's syndrome seem to be at

increased risk of depression. Similarly, Ghaziuddin and Greden (1998) found that autistic children who suffer depression are more likely to have a family history of depression. However, both these studies were small scale case-studies that do not differentiate between endogenous and reactive depression, and while their findings of high rates of depression in family members seems plausible, the explanation for this could simply be related to the difficulties associated with caring for a child with autism and Asperger's syndrome rather than the hypothesised neurological aetiology.

It is therefore not clear whether or not an increased risk of depression is linked to family genetic factors or an awareness of disability in the affected individual and a reaction to social circumstances, adversity or the underlying neurological features. In a recent review of the literature relating to Asperger's syndrome and associated psychiatric conditions, Ghaziuddin (2002) suggests the likelihood of several factors being involved. Gillberg and Billstedt (2000) consider co-morbidity or 'overlap' of affective disorders in autism and Asperger's syndrome to be common, if not the rule, and highlight the anomaly of exclusion criteria in the DSM and ICD diagnostic criteria that rule out the diagnosis of autism in another disorder. These authors maintain that adhering to strict exclusion criteria in the face of mounting clinical evidence does not reflect the problem profiles shown by 'real life patients' and presents major clinical problems for affected individuals and their families.

2.6 Personal experiences of living with Asperger's syndrome

It is the 'real life experiences' of people affected by Asperger's syndrome that would seem to be most neglected in the research literature to date. Although, there have been many reports beginning with Asperger's (1944) original work that

document the unique problems presented by children with Asperger's syndrome, for example, the concept of 'swimming against the tide', and the identification of odd communication skills, social awkwardness, and 'surprising contradictions', all making social adaptation hard to achieve (Asperger 1944). However, even though there are a growing number of biographical and autobiographical accounts (Williams 1992; Sacks 1995; Gerland 1997; Willey 1999; Jackson 2002), there has been remarkably little research into the experience of living with autism or Asperger's syndrome from the perspective of the individuals diagnosed or their family members.

One study that did specifically seek personal experiences is an Australian based study by Gray (1997), which examined family life with a child diagnosed with high functioning autism or Asperger's syndrome. Using tape-recorded semi-structured interviews with 53 parents selected from an autism treatment centre, the researcher, a sociologist, uses a social constructionist framework to understand the meaning of parents' constructions of 'normal family life'. This study provides an interesting insight into the variations in the perception of 'normal family life' and the understanding of how most of the families operated under considerable stress and difficult circumstances. Gray (1997) found that parents' experiences and understanding of normal family life was linked to factors such as their child's ability to socialise, the emotional quality of their interactions among family members, and the rituals and routines compromising their perceptions of what normal families do. He described the activities and interactions cited by parents as evidence for or against normality as being enacted in the context of daily activity where family members had to deal with the problems presented by work, schooling and a variety of service organisations. The study is significant given the lack of

research directly involving the views of those affected. However, the research question and sociological framework meant that those views were being sought to answer a specific question rather than allowing participants to direct the focus of the study. It is likely that whether or not parents construct their families as being normal or abnormal is not of foremost importance in their daily lives, especially given the fact that Gray (1997:1102) describes most of these families as “*operating under considerable stress, some enduring extremely difficult circumstances*”. As the sample group was solely drawn from an autistic treatment centre, these findings, like many other research studies (including Asperger’s (1944) work), may be biased towards those children with Kanner’s autism rather than Asperger’s syndrome and/or families that are having difficulty coping with everyday life thereby excluding individuals and families who may be coping better. In addition, Gray’s study focused on parents of children, not adults and did not seek the views of the children themselves.

Other research studies that provide insight into the lives of *adults* with Asperger’s syndrome are those by Wing (1981), Tantum (1988a, 1988b), and Wolff (1995). However none of these studies explored the personal views of people with Asperger’s syndrome, although they all describe, in varying degrees of detail, case studies of families and individuals. For example, in her seminal paper published in 1981, Wing described 34 cases of children and adults; 28 male and 6 female, with Asperger’s syndrome. Wing’s cases had mainly been referred to psychiatric services but a few had been identified through her previous population study with Gould (Wing and Gould 1979). Most were impaired in intelligence and none gifted, and a number had shown the features of infantile autism in the early years before developing the characteristics Asperger had described. Hence if diagnosed

today using the ICD-10 (World Health Organisation 1993) or DSM IV (American Psychiatric Association 1994), they could not receive a diagnosis of Asperger's syndrome, instead they would be diagnosed as having 'high functioning autism'. It is however acknowledged that this is more of a problem with the diagnostic criteria than with Wing's (1981) sample. Even so, Wing (1981) acknowledges that her patients may have been more seriously impaired than Asperger's and she found the future outlook less hopeful than Asperger had indicated. This is likely due to the year in which she carried out her study, by virtue of the lack of knowledge of Asperger's syndrome at the time; only those with most severe problems were likely to present themselves to clinicians such as Wing. Thus the bleak outcomes in adulthood found by Wing (1981) are unlikely to be indicative of the outcomes in wider population of people with Asperger's syndrome.

In a second case study, Tantum (1988a, 1988b) considered 60 adult psychiatric patients selected specifically due to their 'lifelong eccentricity and social isolation' not previously diagnosed with autism or Asperger's syndrome. Using criteria based on Wing and Gould's (1979) triad of impairments, Tantum (1988a:780) diagnosed 46 of the 60 patients as *"autistic or having an autistic-related disorder such as Asperger's syndrome"*. Tantum (1988a: 770) describes these patients as all *"profoundly socially handicapped, few had lived independently, had lasting sexual relationships or spent much time in employment"*. Only two out of sixty were living independently and more than a half lived in institutions; only two of the sixty had ever married and less than one tenth were working, and only one had been in continuous employment since leaving school. Therefore, like Wing's (1981) study group, Tantum's (1988a) patients were probably much more impaired than Asperger's (1944), and again the outcome in adult life was much poorer than that

for Asperger's children, and most likely, for many others with Asperger's syndrome today. In his second paper, Tantum (1988b) endeavours to differentiate between Asperger's syndrome and schizoid personality disorder, a debate that was current at the time but discussed less now (Wolff and Barlow 1979; Wing 1981; Wolff 1995). In attempting to answer this question, Tantum (1988b) administered a series of complex and highly structured rating scales (Wechsler Adult Intelligence Scale, Mill Hill Vocabulary Scale and Raven's revised Standard Progressive Matrices) to the first 41 of the 60 isolated and eccentric patients described previously. Where possible he included parents in the testing process using a questionnaire or interview based on the Medical Research Council's 'Social Psychiatry Unit's Handicaps, Behaviour and Skills Schedule'. Tantum (1988b) compared relatives and patients answers and discarded questions where there was not significant concordance between the two sets of answers. It seems a pity that these differences could not have been incorporated or explored further in an attempt to understand the differing perspectives of patients and parents; a drawback of using highly structured quantitative research methods. Tantum (1988b) concludes that his results demonstrate that Asperger's syndrome is a distinct syndrome from schizoid personality disorder. This contrasts with the views of Wolff (1995) who uses the two terms synonymously.

Whilst Wolff's (1995) research considers children and adults with schizoid personality disorder, these children's similarity with Asperger's (1944) descriptions make it worthy of inclusion. Wolff, a child psychiatrist, conducted a series of studies during her clinical work over a period of thirty years (Wolff 1964; Wolff and Barlow 1979; Wolff and Chick 1980; Wolff and McGuire 1995). The results of these studies are brought together by Wolff (1995) in her book entitled 'Loners', in

which she describes a group of children originally diagnosed as 'schizoid' seen in her child psychiatry clinic and followed up over a twenty-year period. It is clear that whilst Wolff's (1995) patients are classified as having 'schizoid disorder of childhood' she identifies these patients as akin to Asperger's 'autistic psychopathy'. In 'Loners' Wolff (1995) discusses in detail the difficulties and doubt surrounding the different classifications and overlap between her patients and those described by Asperger (1944), and Wing (1981), but Wolff (1995) herself prefers the term 'schizoid' over 'Asperger's syndrome'. Early in the text Wolff (1995) outlines her intent to use the term 'schizoid' for the children she describes, although without explanation half way through the book she refers to 'Schizoid/Asperger disorders' and towards the end reverts back to using 'schizoid'; perhaps demonstrating her own uncertainty over which term to use. Whilst Wolff's choice of the title of 'Loners' to describe her schizoid patients may be appealing, unfortunately it is not explained or defined and although undoubtedly the term 'fits' with one aspect of many of those she describes, it does not fully encompass what it means to have schizoid personality disorder (or Asperger's syndrome). The title 'Loners' also somewhat contradicts her own finding that one quarter of 47 men and women followed up had married by the age of 27, and the overall finding that social adjustment in adulthood was "*relatively good*" (Wolff 1995:52). In addition, some of the cases she describes in detail appear to be relatively 'sociable' people. However, this does not detract from the importance of her work that was carried out over an impressive number of years, following up 33 schizoid girls at a mean age of 27 years, 19 schizoid boys at a mean age of 22 years (Wolff and Chick 1980) and then 32 schizoid boys at a mean age of 37 years (Wolff et al 1991). All of these follow up studies had matched control groups of boys or girls also referred to the

child psychiatry department but given different diagnoses. Wolff points out that since all the subjects had been referred to child psychiatry as children (mean age of 10 years) they were not representative of the general population and the degree of social impairment of those who formed the control group is bound to be greater than for people in the general population. However, it is interesting to note that her 'subjects' generally had better social outcomes in adulthood than either Wing (1981) or Tantum's (1988a, 1988b, 1991) patients.

Wolff and her colleagues interviewed participants using semi-structured interviews with systematic and pre-coded questions about work, social, marital and sexual adjustment, physical and mental health, alcohol consumption and antisocial conduct to assess young people's life adjustment as well as the core features of schizoid personality. In addition, like Tantum (1988a 1988b, 1991), they used several highly structured rating tests: Eysenk's Personal Inventory (a test for intro- and extroversion); Mill Hill Vocabulary Scale and Raven's Matrices (intelligence tests). The results of these studies showed considerable variations in outcome for both boys and girls in adulthood. Wolff suggests that the individual differences were in part determined by the young people's ability levels and their educational achievements, but also by social and family background and their life experiences, but she acknowledges that her studies could not elaborate further on just what made the educational, social and family factors protective (Wolff 1995). Overall the findings were interpreted by Wolff (1995) as indicating considerable stability over time of the syndrome. She also concludes that affected children were similar to those described by Asperger (1944). Wolff (1995) compared her findings to those of Tantum (1991) and in contrast to his findings, as already mentioned, among her 49 subjects (32 men and 17 women) only one was in residential care, over half were

working relatively well and over a quarter had married by the age of 27. Wolff (1995) concludes that unlike the findings of Wing (1981) and Tantum (1991) her findings were in greater agreement with Asperger's own impressions of improved social adaptation in later life. Thus Wolff (1995:52) states,

“The condition Asperger first reported is clearly wide ranging in severity and it is very likely that most affected young people cope much better in later life than recent studies of Asperger's syndrome, as defined by Wing and others, have suggested. This should give hope to parents, teachers and the young people themselves”.

Whilst these studies make important contributions to understanding people with Asperger's syndrome, they have not directly sought or reported the views and subjective experiences of adults with Asperger's syndrome. Neither do they address the ethical and practical issues of involving participants with Asperger's syndrome in research.

2.7 Gaps in the research knowledge

As demonstrated in this chapter, there is a growing body of research related to Asperger's syndrome. However, problems of definition and diagnosis and the use of differing labels confounds research methods as different people use different definitions and this can lead to some conflicting findings. Much of the existing research has focused on the diagnostic, aetiological, and epidemiological concerns and there is a lack of research considering experiences and outcomes in adulthood for people with Asperger's syndrome and their families, possibly due to the relative newness of the diagnosis, as well as the potential difficulties of accessing and interviewing participants with Asperger's syndrome in research. Also the more able group of people with Asperger's syndrome do not fit easily with many research

agendas considering individual and service needs, thus they remain a largely 'research hidden' group, although there is increasing recognition of educational needs of children with Asperger's syndrome and a significant amount of research is ongoing in this field (Fullerton et al 1996; Jordan 2001). However, educational studies tend to focus very much upon children and in general very little research considers what happens to these individuals and their families in adulthood. The studies, already mentioned, that have focused on adults (Wing 1981; Tantum 1988a, 1988b, 1991; Wolff 1995) tend to include sample groups drawn from psychiatric populations and therefore these studies have a sample bias towards people presenting with significant mental health problems as opposed to those who have never received a psychiatric referral and may show better social adjustment and mental health. There is thus a noticeable lack of research into the experience of living with Asperger's syndrome or having a relative with Asperger's syndrome. In addition, the studies that have been carried out tend to use structured data collection methods with pre-formed aims and objectives, and the concerns and interests of the researchers may not always match the concerns and interests of participants. There are no population studies that have looked at the prevalence of adults with Asperger's syndrome, and in addition there is no reliable information about the extent to which their particular characteristics are positive and adaptive; although there is a growing body of literature relating Asperger's syndrome to mental illness suggesting a maladaptive vulnerability (Ghaziuddin 2002). There is no apparent research evidence that informs us whether the diagnosis is helpful or necessary for all and only limited discussions about the potentially negative side of this diagnosis, whether or not such a label might potentially hinder individuals psychologically,

socially, educationally or professionally (Baron-Cohen 2002; Molloy and Vasil 2002).

The present study aims to add to the current body of knowledge by allowing participants to shape the focus of the data and by exploring their main concerns. Thus the study began with an exploration of the experience of living with Asperger's syndrome as told by young adults and their parents. The emerging concerns were about living with a non-obvious disability, being misunderstood and *not quite fitting in* to the everyday norms of social living, that is, expectations of how people should think, behave and interact with one another. The emerging data thus directed further exploration of these key concepts in theories of being different; this literature is outlined in chapter seven.

2.8 Summary

This chapter has set out the main tenets of the 'technical' literature around Asperger's syndrome, including the historical background, existing debates, psychological theories, and current research. The lack of systematic enquiries about the experience of living with Asperger's syndrome from the perspectives of those affected is highlighted, as are the lack of qualitative studies in this area. The current study addresses this imbalance in the focus of research by exploring the views of young adults with Asperger's syndrome and their parents from a qualitative perspective. The next chapter will detail the methods used to carry this out.

Chapter three

Methodology

3.1 Introduction

This chapter will present the methodological approach and methods that were used to investigate the experiences of young adults and their parents 'living with Asperger's syndrome'. An overview of the grounded theory approach and rationale for choosing this methodology will be explained, followed by step-by-step detailing of how this study was carried out, including: the beginning, the profile of participants (Appendix 2a), sampling procedures, data collection methods and sources of additional data, the way in which data were analysed and how the theoretical hypothesis of *not quite fitting in* developed from the data. Finally, questions of evaluation in relation to the quality and trustworthiness of the study will be considered. Ethical and practical issues encountered throughout the research process will be reflected upon in the following chapter.

3.2 Grounded theory methodology

The study followed grounded theory methodology, the goal of which is to discover participants' main concerns and to conceptualise how they continually try to resolve or cope with them (Glaser and Strauss 1967; Glaser 1978, 1992, 1998; Strauss 1987; Strauss and Corbin 1998a, 1998b). The name 'grounded theory' underscores the main tenet of the methodology, which is the generation of theory from the data. Other core features of grounded theory methodology used in undertaking the study include the inter-related process of theoretical sampling, data collection and constant comparative analysis. A further fundamental property of grounded theory is the idea that 'all is data', which means that everything and anything relevant that helps the researcher to generate or explore the emerging theory in a certain area can be considered 'data', as well as interviews or observations (Glaser and Strauss

1967; Glaser 1998; Strauss and Corbin 1998a). These strategies, and how they guided the present study, are discussed in detail throughout the chapter.

3.2.1 Rationale for grounded theory methodology

In this section I will set out why grounded theory methodology was chosen as the methodological framework from which to conduct this study, as well as the key similarities and differences between other approaches frequently used in qualitative research, namely, ethnography and phenomenology.

In reality the study could have employed a number of different approaches to gain a better understanding of the experiences of young adults with Asperger's syndrome and their parents. For example, a main concern of phenomenology is the 'lived experiences' of participants and an interest in how they perceive their world, which is suited to the aim of the study. However, at an early stage of the research process I read the original book by Glaser and Strauss (1967) 'The Discovery of Grounded Theory', which seemed to me remarkably relevant to today, it captured what I wanted to do and provided a framework from which to begin the study of a relatively little known about area.

Like the other main qualitative approaches, grounded theory methodology provided a systematic yet flexible approach to the research process. This was considered important in undertaking an area of study involving people with a little known and complex disability. In other words, I wanted to have the flexibility to be open to concerns of participants, whilst also having structure and guidance about how to carry out the study. As already mentioned, the grounded theory approach often shares with ethnography and phenomenology the study of phenomena from the

viewpoint of participants (Parahoo 1997). Whereas ethnography is derived from anthropology and thus places an emphasis upon culture, phenomenology emphasises a descriptive psychology, based on the philosophy of Edmund Husserl (Koch 1995). Phenomenology is thus concerned with the 'lived experiences' of people as they construct meaning from their experiences, and rejects empirical notions of causal systems than can be objectively observed (Koch 1995). Thus conclusions drawn from ethnographic and phenomenological studies tend to be descriptions of individual lived experiences written as narrative texts. Grounded theory studies are also often concerned with the meaning that people assign to their own experiences but not exclusively so. Furthermore, whilst 'descriptive understandings' achieved through phenomenology and ethnography are important research objectives, this is not the core objective of grounded theory. Thus, a major difference between grounded theory and these other approaches is the emphasis upon theory generation (Strauss and Corbin 1998b). Glaser (1992:17) asserts that grounded theory is: *"a rigorous, orderly guide to the development of theory that respects and reveals the perspectives of the subjects in the substantive area under study"*. For the purpose of research, Strauss and Corbin (1998a:12) state that the term 'theory',

"... denotes a set of well developed categories (e.g. themes, concepts) that are systematically inter-related through statements of relationships to form a theoretical framework that explains some relevant social psychological, educational, nursing or other phenomenon".

In other words the generation of a 'grounded theory' is derived from the identification of concepts and categories in the data as researchers aim to develop theoretical understanding of the emergent patterns and relationships among key factors, such as, behaviours, attitudes, understandings, and conditions. These are

theoretically linked to build a framework to explain the ‘core category’. The core category is the central concern of participants in the study. Therefore, in grounded theory methodology, the aim is to move beyond narrative description towards generalisability at an abstract level.

In summary, grounded theory shares objectives and methods with other qualitative approaches such as ethnography and phenomenology. The study could have adopted these, and other, approaches in seeking to address the main aim of understanding the ‘lived experiences’ of participants. These methodologies have consistent but different purposes. As its name suggests, grounded theory is concerned with the development of theoretical understandings, and rather than being a research method in itself, it is an end in itself, thus grounded theory studies may employ phenomenological research methods among other approaches. For the purposes of the study, grounded theory offered a methodological framework that could guide the methodological process and the generation of findings in an area of ‘uncharted territory’. This approach enabled the findings to be rooted in the data so to reflect the ‘lived experiences’ and concerns of the participants, that were raised to an abstract level and allowed the core finding of *not quite fitting in* to be compared and integrated with appropriate existing literature and other theoretical perspectives.

3.2.2 Epistemological underpinnings

In this section, my stance with regard to the epistemological underpinning of the study in relation to grounded theory methodology is stated. This is being discussed here as controversy exists about the relevance of theoretical frameworks to research (Glaser 1998; Darbyshire 2000). For example, Darbyshire (2000) warns of the ‘tyranny of the theoretical framework’, and urges researchers to examine what it

adds to a study. He questions why theoretical frameworks are so often insisted upon, suggesting some researchers include this as an 'arbitrary hoop to jump' to show the successful transition to scholar/researcher rather than for establishing a sound grasp of research traditions or the legitimacy of method. Finally, Darbyshire (2000) suggests that theoretical frameworks should only be used in so far as it informs the research process and outcome. In relation to grounded theory, Glaser (1998) is particularly critical of the perceived role of 'symbolic interactionism' in grounded theory. In developing 'grounded theory', the symbolic interactionist school of thought underpinned Strauss' academic background, whilst Glaser brought the rigors of quantitative analytical research methods, and together they attempted to close the gap between theory and empirical research (Glaser and Strauss 1967). They did not limit their 'methodology' to any particular approach and directed their book towards both qualitative and quantitative forms of data (Glaser and Strauss 1967; Glaser 1998). Within the major grounded theory methodological texts (Glaser and Strauss 1967; Glaser 1978; Strauss 1987; Strauss and Corbin 1998a) the epistemological basis of the methodology are not expanded upon. Far from emphasising any epistemological stance, Glaser (1998) argues against what he terms the 'rhetorical wrestle'. He states that grounded theory is only a general method and his advice to researchers is to, "*simply get on with the research*" (p35) and furthermore, "*the wrestle is a waste of time, tiresome and goes nowhere. It detracts from the productivity of the method [...] choosing grounded theory is all that's necessary*" (p35).

Nevertheless, the philosophical basis, or the major tenets, underpinning grounded theory methodology can be found within the symbolic interactionist school of social psychology. For example, like Glaser and Strauss' (1967) description of grounded

theory, the position of symbolic interactionism is *“the meanings that things have for human beings are central in their own right* (Blumer 1969:3). Thus, like Glaser and Strauss (1967), Blumer (1969) also highlights the importance of research that ‘steers away’ from preconceived notions of what’s going on. Furthermore, he emphasises the role of developing theoretical ways of understanding the social world. Thus says Blumer (1969: 47-8),

“Symbolic interactionism is a down-to-earth approach to the scientific study of human group life and human conduct [...] to raise abstract problems with regard to that world; to gather necessary data through careful and disciplined examination of that world; to unearth relations between categories of such data, to formulate propositions with regard to such relations; and to weave such propositions into a theoretical scheme”.

Blumer’s description of the perspective and research method of symbolic interactionism is remarkably similar to the grounded theory method. Thus, there seems to be some tension between the obvious links to symbolic interactionism, and Glaser’s (1998) objections to the ‘takeover’ of symbolic interactionism by researchers who assume that grounded theory is a symbolic interactionist method. Initially confused about the epistemological underpinnings of the study, I followed Glaser’s (1998) advice to ‘simply get on with the research’. However, in exploring the roots of grounded theory and in looking at Blumer’s (1962, 1969) writings on symbolic interactionism (by which individuals are viewed as interacting in a symbolic and socially structured world), I first became mindful of a possible connection with people who have difficulties in interacting ‘symbolically’. For example, I noted in an early memo,

‘I am unsure of how symbolic interactionism fits with my study. However, it is interesting to consider the premise that ‘people attach meaning to and interact through shared symbolic meanings towards the things and people encountered in everyday life’. I wonder how this relates to people with

Asperger's syndrome who may not understand commonly 'shared symbolic' meanings'.

[Memo 12/10/1999]

Symbolic interactionism therefore seemed to be of interest for a study that sought to understand the experiences of, and the consequences for, people who have subtle difficulties communicating effectively with others and interacting symbolically and socially. However, it was not until the later stages of the study when comparing the findings to other relevant literature that this re-emerged as an area to both inform the findings and to take a further critical look at the premises of symbolic interactionism (see chapter eight).

The focus of the chapter will now turn to documenting the actual methods used to explain how the study was carried out and how the central finding *not quite fitting in* emerged.

3.3 Methods

This section of the chapter describes the ways in which the study was carried out including, gaining access to the field of study and participants, profile of participants, the sampling procedures, data collection, alternative data sources, data analysis and how the theoretical hypothesis of *not quite fitting in* emerged and developed. Finally, evaluative questions about the study's quality and trustworthiness are addressed in relation to the overlapping concerns of dependability, credibility and fittingness/transferability (Glaser and Strauss 1967). In writing about the methods it is worth noting that within grounded theory, data collection, analysis and integration of theory occur concurrently and therefore whilst each stage is described separately, in reality these are not clear or discrete

stages. Thus there is some overlapping of the procedures that were carried out that occurs throughout the chapter.

3.3.1 Beginning

As described in chapter one the idea for the study emerged whilst working for a small charitable organisation providing information, advice and support to families affected by autism and Asperger's syndrome. Gaining access to the field of study was relatively easy as I was in daily contact with people affected by Asperger's syndrome. It was during this time that I became aware that adults with Asperger's syndrome and their parents appeared to be a 'hidden' group of people with seemingly unmet needs. The research proposal for the study was tentatively developed and ethical permission was sought and gained from the University Research Ethics Committee (Appendix 4).

During the three years I worked with the charity, I made many contacts with potential participants and people who knew of potential participants. Nevertheless, whilst it was possible to identify a potential pool of participants, it was not always apparent who within a family was the person to contact first; young adult or parent? Since the study sought the perspectives of individuals within both groups it seemed appropriate to interview young adults *and* their parents. Unable to fully resolve the issue, the decision regarding who to contact first was made on a case by case basis. Generally, when a member of staff at the society or I knew the young adult personally, I would speak to the young adult first. When it was a parent, whom a colleague or I knew personally, I would approach the parent first. Some approaches were made opportunistically at support group meetings or during telephone enquiries made to the society. Where the young adult was contacted first, I allowed

them to make the decision regarding whether or not I could contact his or her parents, and likewise, for parents contacted first, I asked their advice about whether or not to make contact with their son or daughter.

I found that it was not possible to interview all young adults and parents from the same families. This was because, for a variety of reasons, not all young adults or parents wished for the other family member to be included. Reasons included, five young adults requested that their parents not be contacted for personal reasons, one set of parents lived too far away, one parent declined participation without explanation, three parents felt that their son or daughter would not cope well with being interviewed, two young adults were not aware of their diagnosis, and one young adult was living in residential care over 200 miles away. The total number of families where both the young adult and parent/s were included jointly was 11 out of 25, of these 6 parents and young adults were interviewed simultaneously and 5 on separate occasions. The number of families where only the young adult or parent/s was interviewed is 14 (7 young adults, and 7 sets of parents). For a participants profile and an interview profile see Appendices 2a and 2b. The ethics of whom to approach first in a study of this nature is reflected upon further in chapter four.

3.3.2 Participants

Participants included young adults with Asperger's syndrome and parents of young adults. Both young adults and parents were interviewed because a) I wanted to understand the perspectives of both, and b) the views of both groups were not found in the research literature. Twenty-five families with a young adult aged 18-35 years believed to have Asperger's syndrome are represented in the study (24 had a

clinical diagnosis and 1 young adult had been informally ‘diagnosed’ by his parents). Of these families eighteen sets of parents (13 with one parent and 5 with both parents) and 18 young adults were interviewed, and 36 primary face-to-face interviews and 6 follow interviews took place (total 42 face-to-face interviews) with a total of 41 participants (18 young adults and 23 parents) representing 25 families. For the purpose of further exploring issues emerging in the analysis, 6 repeat face-to-face interviews and 8 follow up telephone interviews were carried out (see Appendix 2b).

3.3.3 Sampling methods

Initially a combination of ‘convenience’ (Higginbottom 2004) and ‘selective’ (Strauss 1987) methods of sampling participants were used. When analysis commenced, ‘theoretical’ sampling of ‘incidents’ across the data became the major sampling strategy. These sampling strategies will be discussed in turn. First, selective and convenience sampling methods were used simultaneously to start the study process to identify the issues, themes and concepts that needed further exploration. Higginbottom (2004:15) defines ‘convenience’ samples as *“participants who are readily available and easy to contact”*, and Strauss (1987) refers to ‘selective’ sampling as following a ‘calculated decision’ to sample a particular type of interviewee. Thus, in selectively sampling, there were initially two criteria for inclusion:

- Participants had to be aged eighteen and over with a diagnosis of Asperger’s syndrome, or,
- Be a parent of a young adult with Asperger’s syndrome.

This was a largely 'convenience' sample because many of the participants were identified through the charity with which I was working (15/25 families), and 'selective' since potential participants had to fulfil the above selection criteria. This was necessary due to the small numbers of adults who were known to have a diagnosis of Asperger's syndrome at the time of data collection.

Following identification of potential participants and an initial approach, potential participants were sent a letter (Appendix 3a) and an information sheet (Appendix 3b). I then contacted potential participants again by telephone and an appointment to meet was made at a time and place convenient to participants. Theoretical sampling commenced following data transcription and early analyses, when additional sampling, data collection further researched the emerging codes to explore, compare, and explain the open codes. Glaser (1978) describes theoretical sampling as the use of codes elicited from raw data to direct further data collection, from which the codes are further theoretically developed with respect to their properties and connections. According to Strauss (1987) and Strauss and Corbin (1998a) it is the sampling of 'incidents, events or happenings' rather than people per se, that is important with theoretical sampling. Thus whilst convenience sampling provided a relatively large number of participants (41 in total – see Appendix 2b) and considerable data, theoretical sampling led to the re-examination of these interview transcripts searching for incidents that were comparable across the data as well as looking for variation and non typical examples.

The process of theoretical sampling was managed in two ways. First, questions raised in one interview were identified and looked for in subsequent interviews, and

further questions were raised as and when necessary. As the interviews progressed, all interview transcripts were continually cross-examined, and the emerging trends, incidents and concepts constantly compared to each other. Where further questions remained, second interviews were carried out with those participants who demonstrated insight into and an ability to answer the questions being asked during the first interview (6 face-to-face interviews, 8 telephone interviews). Second, theoretical comparisons were made from additional data sources bearing in mind the grounded theory principle that 'all is data' (Glaser and Strauss 1967; Glaser 1998; Strauss and Corbin 1998a). These included informal discussions at support meetings, training events and telephone conversations, and examining a collection and analysis of additional data sources such as published anecdotal, autobiographical and biographical accounts, for example, Willey (1999), Jackson (2003) and Sacks (1985). These additional sources of data collection were not used to generate new concepts but to verify those identified in the primary interviews. This was because the primary interviews with participants yielded enough data to work with and the additional data sources did not appear to contradict the emerging findings. Thus it was simpler to keep the sources of data separate and to focus on the interview data. However, it is recognised that grounded theory methodology does allow for the integration of data from a wide variety of sources.

To summarise, in grounded theory a major strategy is the concurrent processes of theoretical sampling and constant comparative analysis, thus whenever an incident or category was identified in one interview, previously collected interviews were checked/compared for further incidents of that category and then if necessary further explored by second interviews or through examination of the additional data. This process provided opportunities to constantly compare incidents, events and

happenings, to determine how a category varied in terms of its properties and dimensions, and across a wide data set of interviews and published data.

3.3.4 Data Collection

In this section the data collection process will be detailed including the sources of data, the interviews conducted, and the issue of whether or not to audio record interviews.

i) Sources of data

As already discussed, a range of qualitative data was collected, the sources of which included unstructured interviews with young adults and parents, informal discussions at family support group meetings, telephone conversations, and written accounts from informal and published biographies. The interviews are referred to as the primary data sources and all other sources as additional data.

ii) Interviewing process

The interviews took place in either the participants' homes or the charity offices whilst one took place in the garden of a remote country pub. How and where the interviews were conducted varied according to participants' choice and personal circumstances. The reasons for this were for both pragmatic and personal safety reasons (see chapter four). Most interviews (38/42) took place in participants' homes where it was hoped they would feel more at ease; a minority of young adults (3/18) were interviewed at the charity office.

Interviews began by explaining the purpose of the study, asking permission to use an audio-recorder (if used) and giving participants an information sheet reiterating the purpose of the study, what was to be required of them and their rights to refuse

to participate or withdraw at any stage (Appendix 3b). Twenty of the interviews were audio-recorded, 16 interviews were hand noted, and all repeat interviews were hand noted. The original intention was to audio-record all interviews. However, in the early stages of the study four participants stated a preference not to be audio-recorded, which afforded me the opportunity to explore not audio-recording interviews, as advocated by Glaser (1998) and also by Lincoln and Guba (1985).

iii) Audio-recording versus note taking

Glaser (1998) argues that audio-recording is too 'time consuming' in terms of both the laborious task of transcribing and analysing verbatim. He believes this inhibits the grounded theory process by slowing the early analysis that should be commenced during the interview and immediately afterwards in order to 'ground the emerging theory in the data', and guide the process of data collection in ways most likely to 'explore and develop the emerging concepts'. Furthermore Glaser (1998) maintains that it is only the salient issues that need be remembered, and even if forgotten, if relevant will reoccur in further data collection. Glaser is not alone in his advice to disregard audio-recording methods. For example, Lincoln and Guba (1985) also put forward a number of advantages for fieldnotes over audio-recording:

1. Not as threatening to respondents
2. The investigator is kept alert through the note taking process
3. Field notes are not subject to technical difficulties
4. Field notes provide ready access to the investigator
5. The investigator can record their own thoughts allowing immediate insights to be collected.

In practice, I found the non audio-recorded interviews to be useful in quickening and thus moving forward the data collection and early analysis. However, as a relatively 'novice' researcher the audio-recorded interviews provided some safety,

and later became a valuable source for recalling these interviews after long a period of time when writing up the thesis. It is interesting to note that listening to the audio-tapes, even some years after the interviews have taken place, that it is not simply the words that are recalled but as the voices are heard other senses are remembered such as participants' faces, expressions, mannerisms, how they dressed. In addition, my own emotions at the time of interviewing were recalled such as a sense of helplessness, strong desires to help or 'make it better', and feelings of fatigue after a long interview. Furthermore, the replaying of audio-tapes later led to the stimulation of new thoughts and insights.

Thus the question of whether or not to audio-record is not straightforward and there are benefits and disadvantages to both methods. The choice rests on the purpose of the research and the accuracy of the recall of data required. It may also be related, not only to the experience of the researcher, but also the confidence of the researcher in his or her ability to recall salient facts, which may be related to cognitive style or even perhaps the age of the researcher (some research in this area would be interesting). From the perspective of the current study, overall, I feel it worked to have a combination of recorded and non-audio-recorded interviews; this was because for some interviews, particularly the later follow up interviews, I was more interested in exploring in depth specific areas of concern that had arisen in previous interviews. However, there were a couple of interviews that were not audio-recorded and I later regretted not having access to the 'full content'. In particular, there was one interview whereby I had followed Glaser's (1998) recommendations and did not even take notes during the interview, but rather did so immediately afterwards, however, this participant had discussed a number of

complex philosophical concerns that were difficult to fully recall even immediately afterwards. Later in the analysis of findings, I felt it would have been helpful to return to the actual words of this participant. Finally, in order to provide readers with an audit trail of the interviews two full interview transcripts can be found in Appendices 1a and 1b.

3.3.5 Constant comparative analysis

The analytic process of constant comparative analysis was used for the analysis of the data generated by the interviews, fieldnotes and memos. Constant comparative analysis involves (1) comparing incidents across data (2) integrating categories (3) 'delimiting the theory' and (4) writing the theory (Glaser and Strauss 1967: 105).

Following Glaser and Strauss' (1967) method, throughout the process of analysis, each incident was coded (open coding), and compared against previously coded data in the previously collected data. In this way 'categories' of incidents emerged. For example, the categories of 'looking normal' and 'hidden disability' emerged quickly from participants' descriptions of others not recognising they had Asperger's syndrome. These categories were, therefore, closely linked to one another. The goal of the data analysis was to discover participants' main concerns and how they are processing or managing these. In other words, the aim was to identify a 'core' issue through identification of incidents (codes) and categories and then explore the relationships between categories. Thus, key questions asked of the data included: 'What is going on in the data?', 'What is the main concern for each participant?', 'How is s/he coping with it?' and 'What are the consequences?' Constant comparative analysis allowed for these questions to be addressed through

seeking out concepts grounded in the data followed by further questioning of the existing data or generation of new data, when needed.

Constant comparative analysis was used to generate abstract concepts that led to the development of the 'core' theoretical category *not quite fitting in*. This process is explained by detailing the stages of analysis that were used: open coding, identification of a core category, selective coding, and memoing. Data analysis began with transcribing interview recordings and notes and entering the data onto the software programme 'NVivo' and then coding and analysing in depth. It was not always possible, because of the timing of data collection, to carry out detailed analysis immediately, but the material was always scanned at the time and obvious questions or seemingly important issues, that were raised at the time, were carried into the next interview, for example, young adults' 'sense of self'. However, further exploration did not usually involve direct questioning of participants as this would "*preconceive the emergence of data*" (Glaser 1992:25). Rather the questions were in my conscious thoughts, enabling me to be aware of examples arising during a subsequent interview and to probe further. For example, in an early interview a participant had questioned his sense of self asking, 'Who am I?' The same question occurred in a subsequent interview and I was able to ask the participant more about this. For example,

Interviewee: "*I just want to be like somebody else, like somebody walking down the street who is a good looking regular guy that doesn't really have these problems ...*"

Interviewer: "*Problems?*"

Interviewee: "*Always wondering who I am? ...*

Interviewer: "*Can you tell me more about this question, who am I?*

Interviewee: "*I don't know who I am, 'who am I?' That's the hardest question 'Who am I?' I don't know who I am so how can I explain to you who I am? I'm in turmoil about this question ... I wish I knew [...] I'm always looking at other people wishing I was them ... not this person ... whoever he is?*"

Thus, when coding the interview I was able to pick up on recurrent themes and when the opportunity arose in subsequent interviews, probe further, and return to previously collected data. Comparisons across the data already collected were undertaken specifically searching to see if other participants had raised similar issues and so compare 'incidents' that had been identified through open coding.

i) Open coding

Open coding is conceptualising the first level of abstraction. Written data from transcripts were initially coded line by line (Appendix 1c). Early in the study all data were coded in order to find out about the main concerns of participants and if or how they were responding to these concerns. Incidents were identified and then coded, for example, summarised by using a word or words that best described what seemed to be going on. Therefore, incidents were summarised through the use of a word or two words, for example, 'bullying', 'isolation', 'acting normal', and 'not fitting in'. In this way the coding was open to conceptualising all the incidents in the data, which yielded many codes (Appendix 1d). Glaser and Strauss (1967) state that, for grounded theory, concepts need to be both 'analytic', in the sense of being sufficiently generalised, and 'sensitising' in that they are able to yield a meaningful picture. Glaser (1978) expands on this by describing the conceptual code as,

"Coding allows the researcher to transcend the empirical nature of the data – which is so easy to get lost in – while at the same time conceptually accounting for the processes in the data in a theoretically sensitive way" (p55).

Here Glaser refers to the relationship between data and theory, suggesting that the process of coding enables the abstraction of data, rather than the description of data,

for the development of theoretical concepts ‘grounded in the data’. Glaser (1978) offers several ‘rules’ to guide the process of open coding, to keep in mind when examining the data (Table 3.1). By following these rules the analyst is forced to “*think and transcend his empirical view of his data*” (Glaser 1978:57). This raises the analysis from the empirical to abstract level of ‘conceptualisation’ since grounded theory studies are not aiming for description but for summarizing and theorizing general patterns.

Table 3.1 Rules of Open Coding (Glaser 1978:57-60)	
1	Question the data for example, ask: ‘What is this data a study of?’, ‘What category does this incident indicate?’, ‘What is actually happening in the data?’
2	Analyse data line by line
3	The analyst must do his or her own coding
4	Coding must always be interrupted to make a memo of ideas as they occur
5	The analyst should stay within the confines of his or her substantive area and the field of study
6	The analyst should not assume the analytic relevance of any variable such as age, sex, social class, race, skin colour etc., until it emerges

Having carried out extensive open coding and conceptualisation, merging of the codes was then undertaken. Appendices 1b and 1c demonstrate how open coding took place, through which the data was fractured into abstract forms. The open codes overlapped considerably and during the coding process some of them were merged together, i.e. ‘not fitting in’, and ‘can’t quite’ eventually became the core category *not quite fitting in*. Thus the analytic process involved comparing the open codes across the data gathered and the formation of categories of codes. The next process in the development of the analysis is the integration of categories for the identification of a core category.

ii) The core category

The core category *not quite fitting in* was identified after extensive open coding had taken place. Thus as the many emerging concepts were continually compared and more data coded, decisions had to be made on whether to discard, merge or expand categories. Such decisions were made on the basis of their relevance to the core concerns that were emerging; hence concepts were continually modified and renamed. Data analysis went back and forth amongst previously collected data, constantly comparing incidents, constantly modifying, and refining the emerging concepts with the purpose of identifying a core category. The software programme 'NVivo' (Fraser 1999; Richards 1999) made this a relatively simple procedure to carry out and provided a useful tool for coding, crosschecking documents, and managing data. NVivo was also particularly helpful in making the ongoing analysis and codes easily accessible, visual and modifiable.

Not quite fitting in was chosen as the core category because it kept reappearing across the various data sets, both primary and additional sources. In addition it was sufficiently abstract to be able to generalise to other substantive areas. For example, other groups of people who may feel that they do not quite fit in, but it was also open to being refined analytically through integration with other concepts to provide an explanation that was sensitive to the area of study. Thus *not quite fitting in* is a concept that allows variation as well as the main point made by the data, thus, when conditions vary the explanation still 'fits' (Glaser and Strauss 1967).

According to Glaser and Strauss (1967) and Strauss (1987), the identification of a core category is essential in grounded theory methodology in order to focus the

study around a specific area of direct relevance to the data for further exploration and examination. This core category *not quite fitting in* then became the theoretical guide for further collection and analysis of data. Glaser and Strauss (1967) emphasise that this process is intended to both ‘delimit’ (set boundaries) and ‘integrate’ (make connections) the data into a workable theory. The major category identified from the initial phase of open coding was initially that of ‘not fitting in’. However, once this category was explored in further analysis, this was modified to include what has become a pivotal word ‘quite’ so that the central theoretical scheme of the study became that organised around the core category *not quite fitting in*. *Not quite fitting in* was, therefore, the label given to describe the core category as this phrase emerged repeatedly in the accounts of young adults and their parents. As with Glaser’s (1978) rules for open coding (Table 3.1), so Strauss (1987:147) also sets out a number of criteria by which a core category can be chosen, as demonstrated in Table 3.2.

Table 3.2: Criteria for choosing the core category (Strauss 1987:147)	
1	It must be central, that is all major categories can be related to it
2	It must appear frequently in the data
3	The explanation that evolves by relating the categories is logical and consistent
4	The name or phrase used to describe the core category should be sufficiently abstract that it can be used in other substantive areas
5	As the concept is refined analytically through integration with other concepts the theory grows in depth and explanatory power
6	The concept is able to explain variation as well as the main point made by the data; that is when conditions vary, the explanation still holds

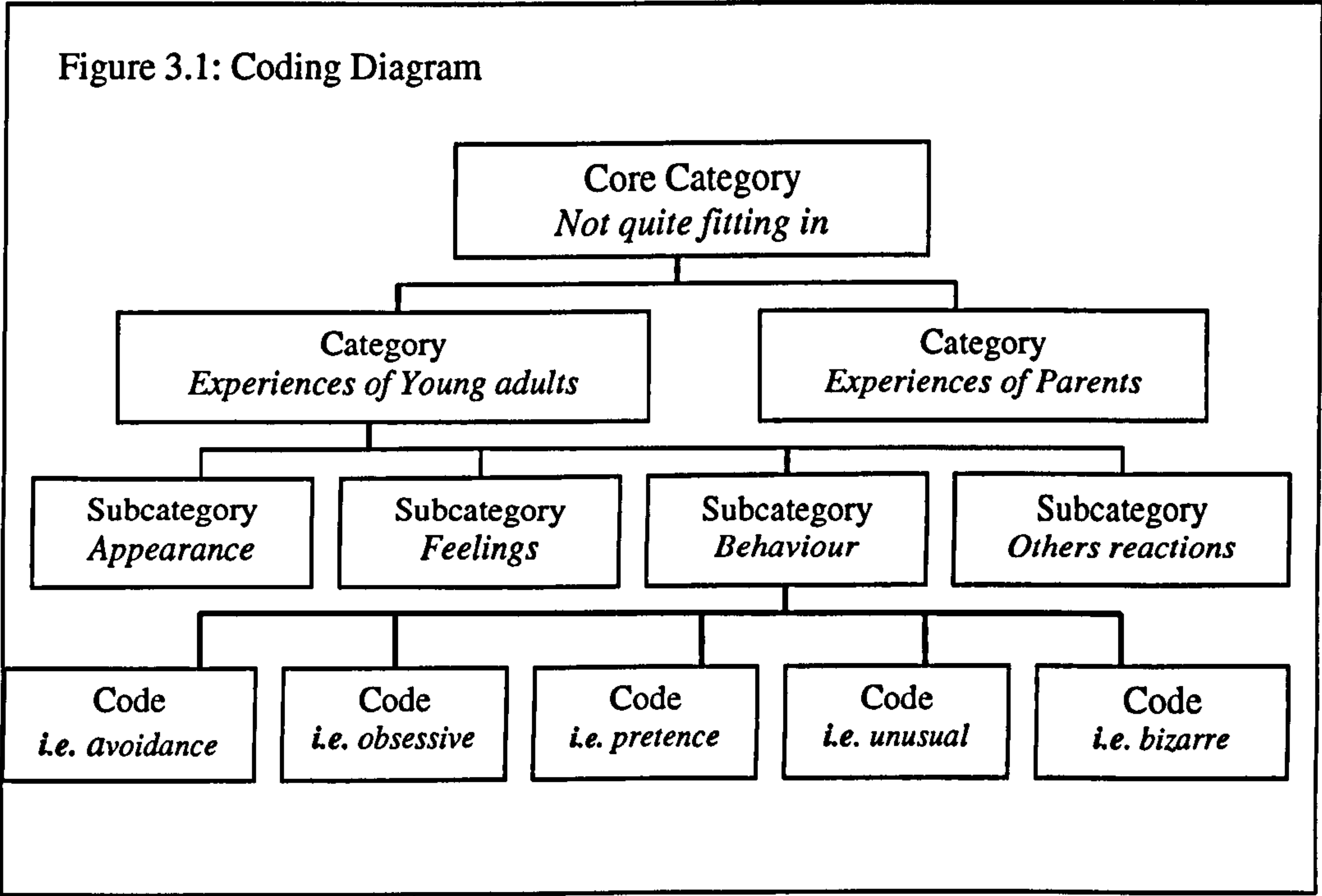
iii) Selective coding

Having identified the core category, selective coding was then undertaken. This was carried out alongside theoretical sampling, whereby the coding of data was guided by the emerging category and ultimately the core category, *not quite fitting in*. According to this strategy, only concepts that relate to the emergent categories and the core category (once identified), are explored further. Those concepts with little importance to the core category are discarded (Glaser 1978). For this reason, any new data considered was selectively sampled with the core category in mind; this is an integral component of theoretical sampling as described later in this chapter. The purpose of selective coding is to create and define boundaries to the analysis of data, referred to as 'delimiting' (Glaser and Strauss 1967), and therefore focus the analysis.

Selective coding involved the gathering of 'focused' new data whereby further interviews (6 face-to-face interviews, 8 telephone interviews) were carried out with the specific purpose to explore gaps/questions arising from the emerging categories. This data were then coded 'selectively', whereby only data relevant to the analysis were coded. Selective coding also entailed careful re-examination of previous interview data as described in the section dealing with 'theoretical sampling' procedures. However, selective coding took the theoretical sampling further by theorising the dimensions and properties of each identified 'selective code'. The narrowing or focusing of the study was particularly important in the face of a large amount of interview data (total = 50 interviews). Glaser and Strauss (1967) caution against collecting 'mounds of data', advising that grounded theory is not about the consideration of all available data, rather "*the method is concerned with generating*

and plausibly suggesting categories, properties, and hypotheses about general problems” (p104). Thus, say Glaser and Strauss (1967:67), “the data need not be important in themselves; only the category which they indicate must be theoretically relevant”. In other words, they suggest that as the study progresses, not all the data need be analysed in detail, but rather focus on only the ‘slices of data’ that may explain or inform the emerging categories.

Thus selective coding, along with theoretical sampling, enabled a reduction in the amount of data. This increased the relevance of the emerging concepts to the emerging core category. Similar codes were merged to form a category and the codes then became explanations of the category. The coding diagram (Figure 3.1) provides an *example* of how the codes generated categories that together formed the core category. For a full list of codes generated see Appendix 1d.



As the analysis continued the category *not quite fitting in* eventually became the core category around which all other categories interlinked. In the example set out in Figure 3.1 the open codes ‘avoidance’, ‘obsessive’, ‘pretending’, ‘unusual’ and ‘bizarre’ are examples of many codes that made up the main category ‘behaviour’ (Appendix 1d) that subsequently developed into a subcategory of young adults’ experiences.

iv) Memoing

Glaser (1998) describes ‘memoing’ as an important aspect of the analytic process in grounded theory,

“Memos are the theorizing write-up of ideas about substantive codes and their theoretically coded relationships as they emerge during coding, collecting and analysing data, and during memoing” (p177).

In Glaser’s view, memoing is important from the early phase of the study as it helps in the process of conceptualising incidents. He regards memoing as *“total creative freedom without rules of writing, grammar or style”* (Glaser 1998:178). Thus theoretical memos can be anything written or drawn, in the ‘constant comparison’ that makes up a grounded theory analysis. Throughout the current study, memos were useful tools for recording, refining and keeping track of ideas that developed, especially when comparing incidents to incidents and then concepts to concepts in the emerging findings. It was through memoing that ideas about naming concepts and linking them to each other developed, and the relationships between concepts were explored. Throughout the research process I kept memos in a variety of ways, including fieldnotes, and as conceptual ideas arising at any stage of the research process. The writing of memos ranged from jottings in notepads to typed ‘DataBites’ within NVivo, which are small pieces of typed annotations that *“the user links to a piece of text in a document”* (Fraser 1999:193). In the writing up of the findings I distinguished between fieldnotes, described as ‘interview memos’

written either during or immediately after interviewing participants, and ‘analytic memos’ that were developed and continually revised throughout the analytic process to refine ideas and link the emerging concepts to the wider body of knowledge. Memos were recorded in a series of notebooks and on sorting through those that had resonance to a developing category or ‘incident’, were then recorded on the computer and printed out. This was visually useful to me in sorting through the many codes and categories that were being developed. Appendix 1e provides examples of how memoing was linked to the process of coding, producing analytic memos.

3.3.6 Theoretical saturation

“Saturation means that no additional data are being found whereby the sociologist can develop properties of a category” (Glaser and Strauss 1967:61).

At a number of points throughout this thesis I have argued that no two people with Asperger’s syndrome are the same. No two people are ever the same and life events will always be experienced and interpreted differently according to the many factors influencing their lives. In a similar way, the experiences of each participant are unique. However, in grounded theory it is not the participants that are compared through analysis, but the ‘incidents’ in the data that emerge as categories, the properties of which are explored through constant comparisons, theoretical sampling and selective coding. Thus, whilst experienced differently, to different degrees, the core category *not quite fitting in* was a universal phenomenon amongst participants, albeit to differing dimensions. Glaser and Strauss (1967) suggest that saturation occurs when gaps in the major categories, are almost, if not completely, filled. In reality, it is not always easy to know if theoretical saturation has occurred and thus for pragmatic reasons I had to make the judgement to stop analysing the

data and begin writing the thesis. On writing the thesis, some further gaps emerged that then required returning to the data to carry out some further analysis and reorganising some of the categories to make better sense for the reader.

3.4 Evaluation of the study

“How will you or anyone else know whether the finally emerging findings are good?” (Miles and Huberman 1994:227)

This section seeks to evaluate how this study addresses issues relating to the quality, or trustworthiness, of the study. The study process began with the broad aim to know more about the experiences of young adults and their parents who were ‘living with Asperger’s syndrome.’ In using a grounded theory approach, the purpose was to develop understanding that is ‘grounded’ in these subjective experiences, which will *“speak to the issues and concerns of those we study”* (Strauss and Corbin 1998a: 265). Thus, in judging the ‘credibility’ of the current study, the concern is with the ‘adequacy’ of the study’s research process and the ‘grounding’ of the findings (Strauss and Corbin 1998a). Or, as described by Glaser and Strauss (1967), the ‘fit’ between data and the finding, that will ‘work’, by being meaningfully relevant to explain the behaviour under study.

This thesis reports on a small study derived from a small number of individuals who may not be representative of the entire population of people with Asperger’s syndrome. However, the issues identified and the experiences of *not quite fitting in* appeared to be real to the participants at the time of interview. Many of the issues identified are borne out by the rapidly increasing anecdotal literature, which suggests a wider ‘applicability’ (Lincoln and Guba 1985) than for the study participants alone.

Glaser and Strauss (1967) discuss evaluation in terms of “*validating the scheme*” in order to determine “*how well the abstraction fits with the raw data and also to determine whether anything salient was omitted from the theoretical scheme*” (p159) They suggest reviewing the scheme for ‘internal consistency’ looking for ‘gaps in the logic’, filling in poorly developed categories, and discarding excess ones. Once the overarching theoretical scheme has been developed they then suggest going back and comparing it to the raw data. They also recommend the researcher tells the story to respondents and ask them to read it and comment on how well it fits their case. To have done this in the current study with original participants was not practical as a considerable period of time had lapsed since the time of interview and I viewed this process as potentially ethically questionable. However, I was able to ask others living in similar circumstances, for example, a mother of a young adult son with Asperger’s syndrome, to review the findings and give comment on the developing thesis.

Many qualitative researchers have considered the question of evaluating qualitative research, and many reject traditional canons by which studies are judged, namely, ‘reliability’, ‘internal and external validity’, stating that such measures are not appropriate for judging the merit of qualitative studies (Glaser and Strauss 1967; Lincoln and Guba 1985; Miles and Huberman 1994; Strauss and Corbin 1998a). In addressing these concerns, Lincoln and Guba (1985) substitute these terms with: ‘dependability’ (reliability), ‘credibility’ (internal validity), and ‘fittingness/transferability’ (external validity). Each of these issues will now be discussed in turn.

3.4.1 Dependability

Lincoln and Guba (1985) suggest that dependability is established through the auditability or demonstration of a clear 'decision-trail'. The purpose of this chapter is to detail the 'decision trail' used in the research process. This, together with direct interview quotes and telling phrases from participants in the findings chapters, and two complete interview transcripts, an interview coding report and examples of theoretical memos in Appendix 1e, provides the reader with an indication of how the findings of the study were arrived at.

Strauss and Corbin (1998a) suggest that by following the same rules for data gathering and analysis, and assuming a similar set of conditions, other researchers should arrive at a similar theoretical explanation as that set out in this thesis. However, I would argue that a number of different points could have been developed as the centre of analysis, for example, 'awareness', which would not necessarily have reached the same outcome. Nevertheless, the decision trail set out in this thesis should allow the reader to see how the findings were reached and be able to judge whether the theoretical phenomenon of *not quite fitting in* is reasonably 'dependable'.

Corbin and Strauss (1990) stress the quality of the data is important for the dependability of a study. On reflection the quality of some of the interviews would have been better if undertaken by a more experienced interviewer. Corbin and Strauss (1990) also state that the quality of a study derives from the analysis, and they argue that the grounded theory analytic process ensures the development of analytic and sensitised concepts, which become 'confirmable and auditable'. Appendix 1 demonstrates the many concepts that emerged from the data, and

examples how they were categorised and then theoretically developed through the process of memoing.

3.4.2 Credibility

This refers to the ‘truth value’ of the study, or as Miles and Humberman (1994:278) ask, “*Do the findings of the study make sense? Are they credible to the people we study and to our readers?*” Lincoln and Guba (1985) suggest a prolonged period of engagement increases the credibility of the study. This has certainly been the case with this study as I worked within the field of an autism charity for three years and have been engaged with the study for a further four years. Furthermore, during this time a close family member had been diagnosed with Asperger’s syndrome and I have informal contact with other parents and young adults living with Asperger’s syndrome. This has helped keep the issues identified by participants ‘alive’ by confirming the emerging phenomenon of *not quite fitting in*, and averted personal doubts over my interpretation of the data. Thus this continued informal contact with people ‘living with Asperger’s syndrome’ has contributed to the development of the thesis.

Strauss and Corbin (1998a) discuss the need for ‘validating the theoretical scheme’ for credibility. By this they mean that the theory emerging from the data should represent those data as an abstract rendition of the raw data. They recommend two ways of validating the scheme similar to those advocated by Glaser and Strauss (1967). Firstly they suggest comparing the scheme against the raw data and doing what they call “*high-level comparative analysis*” (Strauss and Corbin 1998a:159) in order to check that the theoretical scheme explains most of the cases. The second way is to tell the story to participants and ask them to comment on how well it

seems to fit their individual circumstances. This method is commonly referred to as 'member checking' (Lincoln and Guba 1985; Sandelowski 1993b; Miles and Huberman 1994). The first strategy of returning to the raw data was particularly fruitful and I found I was able to confirm both the grounding of my findings and enhance some of the less well-developed categories. The second strategy was not used, as, mentioned earlier, it was not possible or appropriate on ethical grounds to return to participants some considerable time after the interviews. Sandolowski (1993b) makes this point by arguing that returning later to 'member check' can be unhelpful for a number of reasons. For example, people seek to identify only their own viewpoint and not the consensus of opinion. Furthermore, members may not be in a position to check the accuracy of an account, they may have forgotten the information they provided, or they may have moved on from the situations they were in and want to revise or change their stories. Seeing direct quotes from their interview transcripts may elicit uncomfortable feelings such as embarrassment, anxiety, sadness. And finally, the act of being involved in member checking may be difficult since the process itself is socially constructed by the artifices and conventions of social interaction and research. This latter point is significant when returning to young adults with Asperger's syndrome for whom the experience itself may be more anxiety provoking and demand more of them socially than the original interview.

Another difficulty with member checking is that the emerging theory, whilst rooted in individual stories, is also removed from the individual to become a collective integration of a set of abstract concepts into a theoretical scheme. This can be a problem if, as Sandolowski (1993b) says, people are only looking for themselves in the findings. More to the point in respect of this study is Kvale's (1989) emphasis

on credibility as a process of checking, questioning and theorizing, which is the very essence of constant comparative analysis and theory building techniques. The use of alternative data in the forms of informal discussions, conferences, and published biographical accounts facilitated confirmation of the emergent hypothesis *not quite fitting in* and thus helped to establish further the credibility of the study.

3.4.3 Fittingness/transferability

The issue of fittingness, also referred to as transferability, signifies the generalisability of the findings. In other words, are the findings transferable to other contexts (Miles and Huberman 1994), and do they 'fit'? (Lincoln and Guba 1985). Glaser and Strauss (1967) describe 'fit' as being readily applicable to the data under study. The theory must be meaningfully relevant and able to explain the behaviour under study. Strauss and Corbin (1998a) point out that in using a theory building methodology the language is more about explanatory power or 'predictive ability' rather than generalisability. They describe this predictive ability as the ability to explain what might happen in given situations such as stigma or chronic illness. In consequence, to have fittingness the current study needs to 'fit' the experiences of those 'living with Asperger's syndrome' and be able to bring to life those experiences for other readers. The phenomenon of *not quite fitting in* may not apply to the entire population of people with Asperger's syndrome, although I suggest that some fit, even if only partial, is likely. However, the degree of fit is to be judged by the reader who must accept or reject those parts that are relevant. Glaser and Strauss (1967) argue that theory grounded in data can usually not be completely refuted by more data or replaced by another theory since it is linked too intimately to the data. However, it can be modified and reformulated in the light of new data. Thus the very nature of the theory being developed from the data allows

for fittingness in the current study, not as a fixed absolute but as a process that is open and flexible to withstand further refinement and development.

Finally with regard to the transferability of the findings of this study to other contexts, the concept of *not quite fitting in* quite obviously applies to other groups of people with non-obvious disabilities/illnesses for whom similar dynamics apply. For example, for those with: hearing/visual impairments, attention deficit hyperactivity disorder (ADHD), back pain, cancer, and mental illness. Just how far these findings might be transferable and fit other contexts can be judged and accepted or rejected by readers who have knowledge or experience of these areas. Each situation will inevitably require further research and likely modification of the substantive theoretical ideas put forward in this thesis which is principally about people living with Asperger's syndrome. By integrating prior research knowledge about the nature of Asperger's syndrome and through framing the findings within a symbolic interactionist perspective, I have suggested in the discussion of findings (chapter eight) that there are unique features of this disability that predispose people with Asperger's syndrome to the experience of *not quite fitting in*.

3.5 Summary

In this chapter, the methodological approach, epistemological underpinnings and methods used to carry out this study have been detailed. Furthermore, evaluative questions of the study's quality and trustworthiness have been also addressed. The next chapter will reflect further upon the research process in reflectively exploring the many sensitive ethical and practical dilemmas encountered throughout the study.

Chapter four

Ethical reflections

4.1 Introduction

In this chapter, ethical issues relating to the methodological and practical concerns experienced during the course of the study will be reflected upon. This chapter is set apart from the earlier methodology chapter because several issues of ethical concern arose throughout the research process. Of particular concern was the interaction with people who have Asperger's syndrome, including access and the interview process, an area as yet unaddressed in the research literature. The issues that will be discussed centre around ethical concerns and dilemmas that arose in relation to both participants and the researcher, some of which were separable and some inseparable. These issues do not fall neatly into discrete categories, as they overlap to a certain degree. For ease of presentation, the issues will therefore be discussed under the following headings:

- planning an ethical study
- dilemmas of data collection
- researcher-participant relationship
- ethical approval
- impact on the researcher

4.2 Planning an ethical study

This section will explore concerns and problems for the research design, at which stage Mason (1996) calls for researchers to place ethical concerns high on the agenda. A major ethical dilemma emerged early in the research process regarding my own lack of knowledge about Asperger's syndrome, which impinged on my ability to anticipate or understand the potential risks of involving participants with this diagnosis in this kind of study. In discussing ethical issues in the planning and design of qualitative research, Mason (1996:29) states,

“We should be as concerned to produce an ethical research design as we are to produce an intellectually coherent and compelling one. This means attempting not only to carry out our data generation and analysis in an ethical manner, but also to begin by framing ethical research questions”.

Thus, Mason (1996) argues that thinking about ethical issues from the outset of a study whilst formulating the research aims and objectives is important. However as Mason (1996:29) also points out, this is *“easier said than done”*, not least because, *“the changing directions of interest and access during a qualitative study mean that new and unexpected ethical dilemmas are likely to arise during the course of your research”* (Silverman 2001:270). These concerns particularly pertain to the planning of a grounded theory study that is deliberately kept ‘open’ to changes in direction during the course of the study through theoretical sampling and constant comparative analysis. Thus, a key ethical dilemma arises in terms of the researcher’s prior knowledge and understanding of the area of study in relation to producing ‘an ethical research design’ versus entering the field without prior knowledge or assumptions about what will be found.

4.2.1 Prior knowledge and experience

My interest in Asperger’s syndrome developed whilst working with a local autistic society. However, prior to joining them, not long before the study began, I had little experience or knowledge in the area of Asperger’s syndrome. Thus, I came to the study with a rudimentary understanding of the nature of participants’ potential problems, or indeed, the difficulties that I might encounter when interviewing young adults or in talking to their parents. A ‘Glaserian’ grounded theory approach (Glaser 1978, 1992, 1998) would look favourably upon entering the field of study with little or no presupposing ideas so as not to impose ‘forced, preconceived, full

conceptual description' (as opposed to the 'emergence' of a 'grounded' theory) (Glaser 1992). However, as mentioned earlier, entering this particular field with no preconceived ideas was also problematic, both ethically and practically. For example, I engaged with participants in a privileged and 'powerful' position as a researcher, which was endorsed by my position working for the autistic society and by the fact I was qualified as a health visitor. Thus, whilst I initially came with little knowledge of participants' situations, participants themselves may have had assumptions about my role and level of expertise. Johnson and Clarke (2003:429) highlight the issue of the participant's expectations,

"There is also the question of how the participant perceives the researcher's role [...] If the participant has an expectation that the researcher will enact the role of nurse, this will inevitably put the researcher under considerable pressure to 'step out of' the researcher role into the role of nurse and possibly even counsellor" .

I experienced this type of expectation from participants on a number of occasions. For example, I was sometimes asked questions such as, 'What do you think?' or 'What should I do?', whilst in fact, I had little understanding of the issues for participants or how I, or others, could help them. Thus, in setting out I did not know the likely implications either for participants or for myself in carrying out the research. This was particularly challenging ethically as I was entering into an area with potentially 'vulnerable' people. This assumption about 'vulnerability' was made on the basis that 'social and communication' impairments are two major criteria for being diagnosed as having 'Asperger's syndrome'. Thus at the point of commencing data collection, I was aware that young adults with Asperger's syndrome could be vulnerable to the interview process because of their difficulties in social interaction. However, the risk of labelling any group of people as

‘vulnerable’ can lead to these participants being excluded from the opportunity to talk about themselves and issues important to them.

Even describing potential participants as ‘vulnerable’ was problematic. Many young adults were not ‘patients’ under the specialist care of doctors any more than the general population are patients of a general practitioner. Potential participants were not being accessed through a health care setting, but through informal support networks. Even with areas of social or communication difficulty, it is debatable whether this affects a person’s ability or right to make their own choice about participation. Thus, two key questions emerged:

1. Should I draw a distinction between an adult diagnosed with Asperger’s syndrome and an adult who does not have such a label?
2. If a distinction is drawn, does this affect a person’s right to autonomy and self-determination?

This raises the question, should people with Asperger’s syndrome be approached to participate without the researcher having prior knowledge of them, or of the wider issues relating to people with Asperger’s syndrome that may in turn affect their ability to participate? How ethical would it be to exclude young adults from the study based on the complexity of these kinds of questions? It was issues such as these, both philosophical and practical, that led me to seek advice from a number of sources as will be described next.

4.2.2 Roles of an advisory group, academic supervision and peer support

In order to address some of the concerns outlined above, an existing advisory group for the autistic society was approached for advice. The group consisted of the chairman of the autism society (also a parent of a young adult with Asperger’s

syndrome), a second parent, a consultant clinical psychologist, and a learning disability nurse. On looking back, those representatives who were missing were young adults with Asperger's syndrome. However, this omission was not deliberate, as in the early stages I was unsure as to whether young adults could be involved at all. To involve young adults at the consultation stage (had I thought about it) would have probably generated the very issues that I was concerned about in engaging them in the study. With hindsight, including people with Asperger's syndrome would have been respectful and they could have brought new perspectives and insight to the discussions. However, it is possible that this would also have led to issues for the individual and for the group, for example, the levels of involvement and interaction in the meetings may have been difficult to manage (either too much or too little), and the person with Asperger's syndrome may have only been able to perceive issues from a personal viewpoint. In addition, a 'group' meeting might be difficult for some with Asperger's syndrome. Furthermore there could be a risk of creating dependence for someone who normally lacks social contact and friendships giving rise to a sense of loss when the role of the group ended. Although I can look back with the benefit of seven year's experience and accumulated knowledge and speculate over potential problems of involving a young adult with Asperger's syndrome in the research advisory group, at the time I did not know or understand these issues. Although other members of the group had greater understanding, the suggestion of involving young adults at this stage was not made. Also, from the existing literature and other project reports, involving people with Asperger's syndrome in consultation groups did not appear to be common practice (Stirling and Prior 1999; Loynes 2000; Barnard et al 2001). Thus I embarked on the study, relatively inexperienced in this field, relying on the advice and insight of

others to guide me in how best I might access the experiences of young adults with Asperger's syndrome.

Whilst there were clear benefits of consulting and getting advice from such a group, I was also in danger of being too influenced by personal perspectives. I had to recognise that others' agendas conflicted with mine. For example, there seemed some urgency amongst parent advisors for me to 'forge ahead' and help them gain acknowledgement of their needs and better services and I felt that some had unrealistic personal expectations of what the study might achieve. On reflection, it was perhaps unfair to expect parents to have the same focus as myself or be as concerned about the actual research process. I needed time to pace the study, to carefully consider potential and emerging issues. The use of an advisory group might put a study in danger of being 'forced' rather than being allowed to 'emerge' from the data collection if allowed to direct the research questions. However, in grounded theory methodology 'all is data' and I was able to use the insights gained from the group not just as guidance in planning the study but also as data. Thus the use of constant comparative analysis brought the focus back to the data and as data collection and analysis began some of the views of the advisory group became less apparent, whilst other issues they had raised were confirmed in the accounts of participants.

To address the need to frame the study academically and ethically, regular contact with my research supervisor/s and attendance at a monthly postgraduate student support group 'outside of the field' became key sources of advice and support. These forums raised my levels of critical consciousness to the issues outlined above from an objective/academic perspective, and as the study progressed and as I grew

in understanding and confidence, I consulted less with the advisory group and leant more towards academic forms of advice. This was complemented by attendance at a research methods module, many research seminars, and prolific reading of academic texts and papers.

On reflection, if I were to design the study today with my current knowledge and experience of engaging with people with Asperger's syndrome, I feel that I would be less anxious about directly contacting and talking to people with Asperger's syndrome and be better equipped with the skills to interview these participants. However, coming to study without prior knowledge or experience was also beneficial in being open to hearing participants' concerns 'afresh'. Under such circumstances the use of an advisory group in the early stages of a study helped to gain insight into an area that was filled with potential ethical and practical concerns. My advice to learning/other researchers in carrying out research with people with Asperger's syndrome would be to proceed with care and sensitivity towards potential problems outlined in this chapter. It can be helpful in the early stages to seek advice from lay and professional 'experts' in the field, but be cautious as others' experiences and agendas may not always be synonymous with the researcher's aims and objectives, and may not approach ethical concerns as rigorously as the researcher might. Regular academic supervision, student support/training forums, and engaging with the relevant literature are important ways of ensuring each stage of the study is approached with academic and ethical accountability.

4.3 Dilemmas of data collection

There were a number of ethical and practical dilemmas that arose during the data collection process that will be explored in further depth in relation to interviewing people with Asperger's syndrome and their parents. Firstly, the issue of who in a family to approach first, and secondly, should parents be asked to talk about their 'adult' son or daughter at all? This is followed by a reflection on the issues that emerged from the interview process with young adults and parents. Finally, the ethical canons of confidentiality and informed consent in relation to the study will be discussed.

4.3.1 Access to participants and family 'gatekeepers'

The first difficult issue that I encountered, regarding the practicalities of data collection, involved accessing potential participants. One of the aims of the study was to include both young adults and parents in the study but I was unclear as to whom I should approach first. By first approaching parents I was concerned that I might be impinging on young adults' rights to respect and autonomy. Simply by virtue of a young adult's diagnosis of 'Asperger's syndrome', it felt wrong to assume they were too vulnerable to make their own decisions and deny them their self-determination. Alternatively, some knowledge of Asperger's syndrome would mean that by way of having the diagnosis, potential participants would certainly have some degree of impairments of communication and skills of social interaction, thus they may be vulnerable to misunderstanding the purpose and intent of the study, and the potential consequences of participation. The advisory group suggested some young adults may be unable to participate due to problems of anxiety, depression or other mental health problems. The advisory group discussed

the issue of young adults capacity to participate at length and many felt that parents would have an intimate knowledge of their son or daughter and be aware of their potential ability to participate, in terms of being interviewed, their mental health and their ability to take on the nature of the research and possible implications of participation. The consensus of the advisory group was that it was legitimate to use parents as 'gatekeepers' to their son or daughter. However, the question remained about whether or not it was ethically acceptable to approach these potential participants via their parents? There is research literature on 'gatekeeping' that raises the ethics of such roles. For example, Morse (2005) discusses her concern that 'gatekeepers' frequently block qualitative research that seeks to understand the psychosocial needs of 'vulnerable' groups. She argues,

"I believe the greatest gap in health research are those that involve vulnerable participants [...] There is no question that these patients and their relatives should be worthy of special consideration when it comes to access for research [...] but I also believe that patients and their families have the right to respond to participate in research and that paternalistic decisions of ethics committees or other gatekeepers that deny researchers access are not working in the best interests of these patients" (p435).

Whilst Morse (2005) discusses 'gatekeeping' at an institutional level, her concerns about denying access to particular groups can be applied to gatekeepers at differing levels, including in this study, parents. The advisory group that I consulted consisted of three parents, which may have influenced their view on the legitimate role of parents in accessing their 'adult' son or daughter. Thus, I was left feeling unsure of how to proceed. However, in accordance with my study aim (chapter one) I intended to interview parents 'in their own right' to explore their experiences of being a parent to an adult with Asperger's syndrome. Based on this premise, I did feel it was justifiable to approach parents first. Ultimately, such decisions

tended to be made on tentative and pragmatic grounds by doing what felt intuitively 'right at the time'. For example, if a colleague or I knew the young adult it seemed reasonable and right to approach them first. This was especially possible through a social group set up specifically for people with Asperger's syndrome. Here the research was openly talked about within the group. When it was only the parent who was known to colleagues, or me, the parent was approached first. When the young adult was contacted first, I allowed them to make the decision of whether or not I could contact his or her parents. Likewise when parents were contacted first, I asked permission to make contact with their son or daughter. Therefore, based on my first point of contact, the first participant then acted as 'gatekeeper' to his or her family members. By allowing this choice I found that not all young adults or parents wished for the other family member to be included, which I felt duty bound to respect. Five young adults did not wish me to contact their parents for reasons that were not very clear and for which I did not press them to explain - perhaps they were concerned about what their parents might say, or that their accounts may contradict their own. One set of parents lived too far away for me to interview and one parent declined participation without explanation but gave me her daughter's contact details to approach her directly. Two parents felt that their young adult would not cope with being interviewed. One young adult was living in residential care over 200 miles away, and one young adult was not aware of his diagnosis. I do not feel that the issue of who in a family to access first was ever fully resolved in that I did not wish to infringe on young adults ability and right to autonomy, for example, to choose for themselves whether or not to take part in the study. But in the reality of life, I also felt that this sense of 'correctness' had to be balanced against sensitivity towards parents as having intimate knowledge of their son or

daughter, and if as in two instances, they specified that their son or daughter were unlikely to cope well with being interviewed then ‘who was I’ to question their judgement? As such I believed they would hold their adult son or daughter’s best interests at the centre of their decision-making.

On consideration, with regard to the issues of access to research participants there can be many ethical issues to contend with. In particular the roles and motivations of ‘gatekeepers’ and the perceived vulnerability of particular groups of people versus the human ‘right’ to self determination through participation, as well as the right to decline to be involved. Research endeavours must be sensitive to the possible negative effects of conducting research on participants whilst contending with the rights of participants to make their own choices. Finally, in support of this study involving young adults with Asperger’s syndrome, of which there is a dearth of previous health research, I am reminded of Morse’s (2005) argument that the most vulnerable participants are often denied the opportunities to be heard (“give voice”) based on ‘erroneous assumptions’ that are not always in their best interests.

4.3.2 Interviewing participants with Asperger’s syndrome

As mentioned earlier, prior to the study, I had little experience of interacting with people with Asperger’s syndrome, and subsequently experienced a number of difficulties when undertaking the interview with them. For example, at the beginning of an interview I was somewhat startled by the readiness with which some participants wanted to talk to me. I had expected that I would have to spend time establishing rapport, particularly with young adults given their difficulties innate to Asperger’s syndrome in relating to others. Whilst two participants did seem to find it difficult to respond to my asking them to talk through their life

stories and thus needed considerable promptings, others tended to launch into their stories before allowing me the opportunity to provide them with the full pre-interview information regarding the intent and purpose of the study. At these times it felt uncomfortable and perhaps even disrespectful to interrupt participants who had embarked on telling me their 'life story'. In those cases where I insisted on giving the pre-interview information, I sensed some participants were impatient with me and just wanted to be allowed to 'get on' with telling me about their lives. This brought into question just how well informed they were about what they were doing, but also how well informed they wanted to be. I am unsure as researchers we should impose our assumptions on what others need in terms of information. My feeling is that the information should be available in written form prior to participation and that the researcher should offer to discuss this at the beginning of an interview, and indeed at any stage of the research process. However, when encountering difficulties such as I did, with the apparent 'disinterest' in the procedures, I would caution researchers to question whose best interests are being served by the measures being taken - to protect the wellbeing of participant or to protect the wellbeing of the study?

Throughout the interviews, in an attempt to compensate for the obvious power differential during the interviewing process, I followed Finch's (1984) advice to adopt an open ended, less structured strategy aimed at reducing the hierarchical relationship, which gave participants the freedom to tell their 'stories' in their own ways. However, I found that the lack of structure was problematic to young adults' not knowing where to begin. Thus I changed my interview approach slightly by asking participants to talk through their life histories from their earliest memories to the present day. This was to enable participants to have a tangible focus yet remain

open to them choosing which life experiences they wanted to talk about, hoping they would recall the most salient and meaningful events, thoughts and feelings. However, given this freedom to talk about themselves and their experiences, another difficulty arose with the way in which participants gave their accounts. Some went into their life stories in great detail that lasted for hours, during which participants at times appeared to deviate a long way from any obvious point they were trying to make. At these times I was unsure of how much I should interrupt and impose my agenda because I was at risk of taking back any control that I had tried to give them. However, some interview accounts remained very factual, often presented in a short and stilted fashion. At this point it is impossible to know whether these young adults were unable to express, or unable to access their inner thoughts, feelings and emotions. This raises the question as to whether or not the interviewing skills adopted were sufficiently sensitive in accessing these kinds of data, or whether the young adults themselves had limited ability to reflect on their own thoughts and feelings in relation to their experiences. In contrast some young adult participants seemed to focus profoundly on their internal thoughts and feelings, and were able to recall experiences with considerable insight into how it affected them. For example,

“I would often stand in the playground or sit in class and just watch others ... playing together, talking, laughing, joking – having fun. I wished I could join in or have a special friend but I never really did ... I would usually be on my own, just like an outsider looking in. It’s still no different ... always being on my own ... a lonely life.”

[Sebastian]

There were also occasions when participants seemed to be revealing more to me than they perhaps should do in terms of social acceptability and placing trust in me as a relative stranger. For example, one young adult talked about his liking for

watching women urinate and although he stated that he would never attempt to do this in public, I personally felt uncomfortable with this information and was unsure of why he had told me. I did not feel threatened by him in any way but I did feel he was perhaps confiding in me 'too much'. Mason (1996) asks researchers to consider the ethical implications of gaining interviewees' trust in a way that allows them to open up about private issues. On reflection, I am unsure of whether it was altogether a matter of my gaining participants' trust. Many young adults seemed to simply tell their stories with little regard for the regulation of the content, which may be related to an impaired ability in Asperger's syndrome to understand other people's viewpoints (Happé 1994; Baron-Cohen 1995). It seemed that participants who revealed too much personal information were not trying to shock me as the researcher, nor were they deliberately trying to make me feel uncomfortable; rather it seems likely that they were unaware of their impact on me. This then placed a responsibility on me to treat the data with extra care so as not to exploit participants. It also raised the question again as to how 'informed' participants were about the potential consequences of revealing such personal information to me, a person relatively unknown to them. This issue links back to the difficulty I experienced with some young adults at the beginning of the interview in their apparent disregard for the pre-interview information and thus participants not fully understanding the possible consequences of the interview.

4.3.3 Informed consent, confidentiality and anonymity

Ensuring that participants engaging in research are doing so voluntarily, without coercion and in the knowledge they can withdraw at any time, is a fundamental principal of research (Economic and Social Data Service 2005). However, several

researchers have questioned how far consent can ever be truly 'informed' (Johnson and Plant 1996; Mason 1996; Swain, Heyman and Gillman 1998). This seems particularly the case when conducting interviews (Mason 1996; Swain, Heyman and Gillman 1998). For example, Swain, Heyman and Gillman (1996:26) argue,

"The researcher using open-ended interviewing takes a contradictory position which, on the one hand, says to the participants that they are in control, and may disclose at their discretion, but on the other hand, employs techniques which are geared to enabling participants to talk freely and openly about the most private details".

As already highlighted, some participants were difficult to engage in the pre-interview discussion about the aims of the study and potential implications for participants. Thus not only did problems (common to qualitative research) occur, for example, what information to give to participants, but the process of actually gaining informed consent was particularly problematic. Some participants seemed impatient to start telling their stories and I felt pressured to hasten through the preliminary discussion. Thus, I was faced with the dilemma of knowing that as a fundamental principle of research, ethically I was responsible for seeking participants' 'informed consent', to ensure they be as informed as possible about the purpose of the research and the potential implications of being involved and how I intended to use the information they provided. However, I was finding that participants did not seem to share my concerns and did not appear interested in the detail. Thus the process felt mechanical and stilted. Again, it felt as though gaining consent was more for my benefit to satisfy the rigors of the research process and the requirement of the research ethics committee, rather than truly for the benefit and protection of participants. Price (1996) describes her dilemma at her University's requirement for signed informed consent when studying the life history of women

reported for child abuse arguing that signed consents jeopardise participants' confidentiality, by making them identifiable. I also questioned the necessity of 'signed' consent but complied with the ethics committee expectation that this would be done when formally interviewing participants. However, in following the 'grounded theory' mandate that 'all is data' (Glaser and Strauss 1967; Glaser 1998) I also made fieldnotes and memos during telephone conversations and at informal meetings that I did not gain explicit consent for. In doing this I felt uneasy about whether this was ethically 'legitimate' data. However, the coding procedures in grounded theory fracture the data into incidents and become theoretically conceptualised, and thus represent multiple perspectives rather than individuals' perspectives or any one data source. Thus, additional data collected outside of the formal process of interviews, was handled within the analytic process in ways that did not compromise the person from whom the data were derived.

Nevertheless, due to the small size of the field, and the sensitive nature of interviewing members of same families, as well as some young adults' propensity to 'tell all', issues of confidentiality and anonymity were considered to be a high priority in carrying out and reporting the study. The interviews were conducted flexibly, with some parents and their son or daughter interviewed jointly and others separately. I was mindful of the need to be flexible and I would abide by what seemed to be the most natural and best for that particular family. In this respect I found that participants would often take the lead and guide me. For example, when interviewing parents there were occasions when a young adult would wander in and out of the room. As one mother said when her son walked out, "*this bit is too difficult for him to listen to ... that's why he's gone out ... he'll come back when he wants to*" [Sandra, mother of Matthew]. Another time, on arrival at the

participants' home, I was greeted by a parent and told that I could interview her first and then her son separately as the young adult had specifically stated this was what he wanted to do. When parent and young adult interviews were conducted separately, I was aware of the need not to interject with questions that may reveal what another family member had told me in confidence, although with the exception of two families, the stories told were very cohesive and even if perspectives clashed they were not apparently contradictory or revealed as secretive. An exception was a mother who seemed intensely resentful of her son, stating that his difficult ways and lack of sensitivity to others had placed an intolerable strain on her marriage, which caused the marriage to breakdown. On interviewing the son he seemed quite oblivious to the negative feelings his mother held, reflecting his inability to perceive the feelings of others, which generated a source of conflict for his mother. On another occasion a young adult participant talked strongly of 'hatred' for his parents. His father had not mentioned this on previously speaking to him, and during the interview with this particular young adult, I felt quite concerned, as a person and as a researcher, about the very negative way that he talked about his parents. Not only did it feel personally disrespectful to his parents, which did not seem reconcilable with his father's seeming genuine concern for his son, but also as a researcher I felt privy to intense negative feelings that could, potentially, pose a threat to the parents. But the young adult participant had not actually said anything specifically to threaten his parents, or to place them in obvious danger, so I felt unable to talk to them about this without breaking confidentiality. Nevertheless, it did leave me feeling anxious - could the hatred lead him one day to do something that was morally, socially, and legally, unacceptable?

The interviews that took place with parents and without the participation of their son or daughter were intended to focus on parental experiences. However, as mentioned, talk about their adult son or daughter was unavoidable since their lives and experiences were bound together. Mason (1996:57) suggests that researchers,

“... need to recognise that it is not uncommon for an interviewee to reveal stories to reveal what seems like private information concerning third parties whose consent you have not gained”.

Mindful of this I have attempted to be especially careful not to reveal sensitive information regarding third party information or to provide personal details relating to these families in the analysis and writing up of findings. In ensuring this there have been times when interesting data and quotes needed to be sacrificed and have not been used. For this reason the participant profiles are kept (Appendix 2a) brief, outlining participants' pseudonyms, age at interview and age of diagnosis. Whilst greater family detail would perhaps provide interesting background information, I have selected carefully the information required to fulfil the needs of an audit trail without threatening participants' anonymity. Again, the use of constant comparative analysis was a helpful tool in maintaining confidentiality because it provides a way of analysing people's stories, developing concepts and categories that become increasingly abstract and unlikely to be traced to a particular individual.

4.4 Researcher-participant relationship

This section will reflect on issues in relation to the relationship between the researcher and participants. Justification will be made for not using a more participatory research approach and issues of power and gender will be raised, as

well as participants' expectations, and a reflection on for whom the study was undertaken.

4.4.1 Involving participants in the research process

In conducting qualitative interviews some authors recommended that researchers strive for mutually empathetic and respectful relationships between researcher and participant (Oliver 1992; Fine 1998). Oliver (1992) argues, from a disability perspective, that participatory methods are essential to redress the power balance between the researcher and the researched. When conducting the interviews, however, I soon realised that it would be unwise to form relationships with participants that could be misconstrued or give a false impression of the nature of the relationship. This, therefore, excluded the use of a more participatory research strategy whereby participants are encouraged to be involved throughout every stage of the research process. As I began to get acquainted with potential participants through attending charity meetings, support groups and social functions I began to realise very early on that this was unlikely to be possible. At this time I was already experiencing frequent telephone calls to my work number by a young adult with Asperger's syndrome interested in taking part in the study. This young man lacked a sense of time boundaries and his phone calls were persistent and long. I also recognised that Asperger's syndrome predominately affects males and there were also issues of gender to be considered in the participant-researcher relationship. I sensed that as a woman carrying out a study involving a number of young, seemingly lonely men, I would need to have clear boundaries. As a nurse and health visitor keeping 'professional boundaries' has always been integral to my work, for example, I have always withheld disclosure of personal contact details

such as home address and phone number. However, I found this was not normal practice within the small charity I was working for; most of the people working there were doing so voluntarily over part-time hours and were seemingly happy to receive calls at home. I decided not to give my home phone number and address to participants, but since I was collecting potential participants' home telephone numbers and addresses, it could be argued that our relationship was immediately 'unequal', and however much researchers may want to address this problem,

"We have to accept that the entire research process is most often one of unequals and that, as researchers, we retain power and control over conceiving, designing, administering, and reporting the research" (Mauthner and Doucet 1998:139).

4.4.2 Participants' expectations

During the interview process, there were numerous occasions when I felt that participants had higher expectations of the research process, and of me, than I was able to deliver. A few participants wanted and seemingly needed more than an interviewer-interviewee relationship, which I was unable to fulfil. For example, a participant seemed disappointed when during an interview he pointed to my wedding ring and said, *"You seem nice ... it's a shame you're married"*. This apparently lonely young man described how he longed for a girlfriend. With this in mind, I declined his request that we meet up for a series of interviews. I felt apprehensive at not being able to meet his expectations of me, or his need for company, but neither did I want to create a dependency on meeting with me, or too compromise my own safety given his own descriptions of fixations on former 'girlfriends' and his obsession with adult pornographic material. The term 'girlfriends' is used here as the term this participant used. However, it appeared from the interview content that these were not intimate relationships but rather girl

acquaintances with whom he had fantasised as his girlfriends and become unrealistically emotionally attached to. Hence, on this occasion I felt that this participant had an agenda for agreeing to take part in the research that was totally different to my own and I did feel threatened by the possibility that he may have unrealistic expectations of our relationship. Therefore, I considered that strict boundaries were necessary for both his and my wellbeing. It did not seem right to carry out repeated interviews with lonely young participants over a prolonged period. In this context I considered this to be potentially harmful to both participants and to me as the researcher, hence single interviews seemed the most appropriate way to proceed. This raises implications of 'safety' for the lone researcher and the larger element of risk and uncertainty in qualitative research than with more formal methods (Punch 1998; Lee-Treweek and Linkogle 2000) and highlights the need for lone researchers to pay increasing attention to issues of personal safety awareness, such as working in pairs. Researcher safety is further examined later in this chapter.

4.4.3 Who is the study for?

In undertaking my PhD project, I was aware that I would benefit most from the study. However much I wanted to raise understanding for people with Asperger's syndrome and their parents, and however much I sought through my work and publications (Portway and Johnson 2002; Portway and Johnson 2003; Portway and Johnson 2005) to influence professionals' understanding of this disability, I was conscious that my participants were helping me personally more than I appeared to be helping them. I did always try to make a point of explaining this personal benefit to participants, but as with the issue of consent, it seemed that the majority

of participants were not as concerned about this as I was. On reading Finch's (1984) classic critique on interviewing women, I felt some affinity to her words: "*I have emerged from interviews with the feeling that many interviewees need to know how to protect themselves from people like me*" (p80). Here Finch refers to the fact that a lack of understanding of research methods can lead participants to base their trust on the researcher's appearance and approach rather than anything to do with the rigor of the research process. I presented as a friendly female interviewer with time to listen and the credentials of a health visitor and an employee of a local autism charity. Sensitive to this, I was aware of the responsibility I had to protect participants from potential harm or from misrepresentation through both the interview process and from published material. Thus I have tried to ensure that this trust was not misused by misrepresentation of the data or exposing the identity of participants by reporting too much personal detail or by indiscriminate publishing of identifying excerpts of data.

On reflection, as already discussed, although I tried to maximise the participant perspective within the interviews and generation of data, from which the phenomenon of *not quite fitting in* emerged, the relationship between participants and researcher was unlikely to ever be 'equal'. I held the control and power over how to interpret and represent participants' life stories; I chose the 'incidents' to analyse and I subsequently interpreted what their words would say within the context of this thesis. In return, ethically and legally, I have a duty of responsibility to handle the participants' data with care, sensitivity and respect. Thus, efforts were made not to distort participants' words and to make reasonable sense of their meanings, and steps were taken to maintain confidentiality and anonymity. Finally, tape recordings, transcripts and consent forms have been kept secure in accordance

with the Data Protection Act (1998) that regulates the storage and use of personal information.

4.5 Ethical approval

Ethics approval to conduct the study was applied for and granted by the academic institution supervising the research during the period of data collection from which recommendations were made in relation to researcher safety; data storage; and contact with social services (Appendix 4). Whilst these were rational recommendations, they were not without their own difficulties that will be addressed in turn.

The first recommendation by the research ethics committee stated,

“Members of the committee recommended that in the interests of your own personal safety the interviews be done in the offices you described, or if home visits are necessary then they recommend that you be accompanied”.

With regard to this recommendation and to my personal safety when visiting people's homes, being a health visitor, I was experienced in visiting people in their own home and whom I had not previously met. Whilst this could have led me to feel some degree of complacency about my own safety, I felt that many years of training and experience in both inner city and rural areas had enabled me to develop an awareness towards my personal safety as well as how to conduct myself professionally in other people's homes. Thus on entering a house I would adopt a demeanour that is courteous but also alert to signs of danger; maintaining a stance that is non-confrontational and non-threatening whilst also keeping to mind a readiness to withdraw should it seem necessary. I always ensured that someone knew where I was and at what time to expect me to return from the interview. It was not practical for me to be accompanied on all interviews at home because my

two colleagues worked voluntarily on a part-time basis and their own obligations were time pressured. Accompanying me on visits to participants up to 50 miles away was, therefore, not often possible. However, for personal safety reasons I made a decision that I would not interview young male adults alone unaccompanied unless their parent/s were present in the house. There were times when this felt as if I was being overcautious and I was aware that I was judging young adults as being potentially more threatening than their parents, a judgement made simply on the basis of the diagnosis of 'Asperger's syndrome'. This mistrust did not always feel comfortable, especially as I was expecting participants to trust me both in terms of coming into their homes and in how I would handle their personal information, some of which was of a 'sensitive' nature. The alternative was to interview young adults at my workplace as the committee had advised, and I did this on four occasions. However, as I was interviewing people across a large county it did not seem practical or fair to ask all participants to travel to me in terms of cost, time and effort required. A few young adults were simply unable to travel to me due to problems with agoraphobia (n=2) and difficulties in negotiating public transport. Whilst at no time did I perceive myself to be at any immediate risk from participants, on occasion I did feel uncomfortable with the discourse taking place. For example, as mentioned before one young man had no hesitation in discussing his obsession for adult pornographic videos, and another participant's disclosure of his pleasure in watching women urinate.

Thus the issue of my personal safety as raised by the research ethics committee was salient, but not always easily resolved. However, I was aware that this recommendation was for my personal safety as the University had a duty of care for me as a student, just as I did for myself, and for my family. In hindsight, although I

did set boundaries for participants, and myself, in future I would give greater attention to this. My advice to other lone researchers would be to carry out interviews with strangers in their own homes only if necessary and to always do so in pairs. Whilst I relied on my experience as a health visitor in entering other people's homes, I failed to take into account that in my professional role there is often other information available regarding people's mental state from other colleagues and medical records. Thus in many cases as a health professional I am privy to information highlighting potentially dangerous clients and can adapt my approach accordingly. However, working from a small parent-led charity excluded me from such information and thus potentially placed me at greater risk.

The second expectation by the research ethics committee stated,

“As with all recorded interviews the committee expects the audio recordings to be erased when you have finally analysed the data”.

Whilst this is a reasonable requirement, the research process has taken place over a prolonged period of time and therefore the audio recordings were stored for a long period of time and have had to be transported with me on several moves of location. It is intended that the recorded interviews will be erased after the thesis has been examined.

Finally, the committee also recommended,

“That you ensure that you have adequate contacts with social services in case you need to use that network should you detect some issue which merits help”

As a practising health visitor in the local area, I was acquainted with social services and with their criteria for intervention. I, therefore, had contacts within social services, and I was aware of how to contact them. On discussing this with a social worker, he seemed doubtful whether social services were either appropriate or

would be able to support these young adults, this was because the kinds of services possibly needed were unavailable. In terms of the issues that arose during the study I was able to draw on the support networks of the local autism charity who offered a wealth of information and support to both parents and adults with Asperger's syndrome, and through this two young adults joined a social support group for adults with Asperger's syndrome.

4.6 Impact on researcher

Finally, I will briefly reflect upon the impact of conducting this study for me, the researcher. I had entered this field of study with sensitivity and awareness that participants may potentially be 'vulnerable' and need support through the interview process, but not really knowing what was to come, for example, their overwhelming needs and sadness that I would encounter whilst listening to participants' stories. Equally I did not anticipate the impact this would have on me, for example a sense of helplessness at not being able to change anything, and lasting memories of particular participants that are tinged with sadness. Neither was I aware that a child in our family would later be diagnosed with Asperger's syndrome giving a new poignancy and meaning to the reality and experience of 'living with Asperger's syndrome'.

There is a body of literature examining the emotional toll on the researcher in qualitative research particularly when engaging in 'sensitive' inquiry (Lee and Renzetti 1993; Johnson and Plant 1996; Johnson and Clarke 2003). As already described, there were many times when I have felt uncomfortable with one aspect or another of the process of this research. However, prior to starting the research I had not really considered the emotional impact of carrying out the research for myself.

Johnson and Clarke (2003) in their review of researchers' personal accounts found this 'unpreparedness' to be a common theme, particularly when working in 'uncharted territory'. During the period of data collection I felt a strong sense of compassion for participants and a desire to want to intervene in some way on their behalves and I have some enduring memories of some participants and our encounters. For example, on one occasion, I recall arriving at a participants' home and being shown to the upstairs hallway where a dining chair was waiting for me to sit on. The young woman I came to interview sat down on the floor in front of me. She explained to me that this was the only place that she could see me because she was so affected by agoraphobia that she was unable to venture downstairs. Neither could she allow me to enter her bedroom because to do so would mean that I would make her space 'unclean' and she would have to go through an elaborate cleaning routine before she felt comfortable again. Whilst sitting on a 'hard chair' in the hallway I had no choice but to 'look down' upon this 'childlike' woman (who was the same age as me) sitting on the floor with her legs crossed like a little girl, talking to me about her life in a curiously childish voice. I made a note that she seemed 'stuck in time as well as stuck upstairs' [Interview memo 12/11/00]. The whole situation felt most peculiar to me and yet she seemed to accept her situation. I noted in a further interview memo that 'this was her reality that had been encompassed into her everyday life' [Interview memo 12/11/00]. She described her 'story' in such detail that I felt I could visualise her experiences. On listening then and later on re-reading the interview transcript, and even now on reflecting on the interview, I can still hear her voice and feel some physical pain at the sadness of her life. I have often since thought of her.

Through the process of constant analysis and returning to the original data, I have frequently been reminded of and, in a way, have constantly re-lived participants' life stories and the interview experience. It is interesting that reading through the transcripts, interview excerpts, memos and journal notes, as well as occasionally re-listening to the tapes, even some years after the interviews, it is not simply the words that are recalled but as the voices are heard other senses are remembered such as participants' faces, expressions, mannerisms, how they dressed, the sadness and loneliness, desperate parents, and also my own emotions as interviewer such as intense helplessness, feelings of fatigue after a long interview, and strong desires to help or 'make it better'. Johnson and Clarke (2003) raise this as an issue of 'role conflict' linked to the issue of 'reciprocity'. They question the impact of the background of the researcher, for example, nurse, counsellor, and sociologist, on the data collection experience. For example, they suggest that nurses in particular, 'as people trained to relieve suffering', find it difficult to ignore participants' needs and not to respond in the role of nurse. In the normal course of my work as a health visitor, I come into contact with many people who are suffering. The difference in that, in this role, I have some degree of influence and ability to attempt to make provisions to help people but as a researcher, in an area that I was relatively unfamiliar with, I felt disempowered and helpless. This could also reflect the 'helpless' position of many participants. In processing some of the feelings experienced during an interview, discussing these thoughts in supervision was important and very helpful. This function of academic supervision has thus far received little attention in the research literature. However, in relation to clinical supervision some authors have questioned whether the level and type of supervision

generally provided, facilitates adequate emotional support (Davis and Cockayne 2005).

4.7 Summary

In this chapter, I have reflected on some of the ethical and process dilemmas encountered during the research process, of which I had little knowledge of prior to the study. This, coupled with the lack of existing research carried out directly with participants with Asperger's syndrome, meant that issues were difficult to anticipate.

Particular concerns included difficulties of access and of data collection, as well as the rights of potentially 'vulnerable' participants to make their own choices versus issues of potential harm. A main concern centred on interviewing people with communication difficulties, which affected the processes of informed consent, confidentiality and anonymity. Another key issue was that of the participant-researcher 'relationship', which included reflections on dynamics of gender and power. For example, on engaging with the interviews I became aware with some of the younger male participants of a need to 'keep my distance' emotionally and socially. Furthermore, recommendations made by the academic research ethics committee (Appendix 4) were examined and the implementation of these discussed, in particular with regard to my own safety. Finally, the personal impact for me as researcher has been reflected upon, and how some of the feelings and emotions generated were processed through discussion within supervision. As with Johnson and Plant (1996:98), I am *"left with some concerns that [I] found impossible to resolve"*. Thus, throughout the process of the research, difficult decisions emerged with no clear ethical course of action. Some of my decisions were made based on

‘compromise and context’, although always from a ‘considered ethical position’ (Mason 1996). Furthermore, where relevant I have made recommendations to other researchers. In documenting my experiences and the ethical concerns, this chapter has addressed a gap in the literature concerning research involving people with Asperger’s syndrome.

Chapter five

Findings: young adults

5.1 Introduction to the findings

The next two chapters will set out the findings of the study that reflect the experiences of living with Asperger's syndrome as described by 25 families. This first findings chapter will present the findings pertaining to young adults with Asperger's syndrome whilst the next chapter will present the findings in relation to the experiences of their parents. Although the core category of *not quite fitting in* relates to the experiences of both young adults and parents, albeit in differing ways, the findings are separated because in analysing the data, young adults and parents were found to have two distinct sets of experiences and needs. Thus, the purpose of distinguishing the findings concerning young adults and their parents is to present the experiences of both groups of participants as standing 'in their own right'. This supports the intended aims and objectives of the study described in chapter one to consider the lived experiences of both young adults *and* parents.

In this chapter, the findings have been drawn from the lived experiences of young adults, and triangulated by the accounts of parents. An overview of the core emergent category of *not quite fitting in* will first be set out followed by the findings that are categorised into four major categories, all of which form key aspects of the core category. These categories relate to 'how young adults feel about themselves', 'how they appear to others', 'how they behave' and 'how others react towards them'. Whilst these will be presented as separate categories, there is considerable overlap of data across the four categories. This is because they all interlink and influence one another since young adults' feelings drive behaviour. This in turn affects how others perceive and respond to them, as well as how young adults think and feel about themselves and how they perceive others.

5.2 The core category - not quite fitting in

“To a stranger at first glance whether it’s a person I walk past in the street, or somebody who has a reason for coming to my house ... like a friend of my mother’s ... looking at me they would see a perfectly normal looking teenager. So why would that person have any reason to know I was suffering from the ... the lack of social skills needed for coping day to day that’s essential for any social activity in life?”

[Andrew]

The core category of *not quite fitting in* emerged during constant comparative analysis of the data, and was also found as a recurrent theme in the many published personal narratives written by people with Asperger’s syndrome (Holliday Willey 1999; Jackson 2003; Miller 2003). Key aspects to the core category are young adults’ subjective feelings of *not fitting in* alongside their apparent ‘normal’ appearance and sometimes ‘puzzling’ behaviours. The following quote from one young adult participant embodies the connection between ‘feeling different’, ‘looking normal’ and ‘puzzling behaviour’,

“I might not look as if there’s anything wrong but there is...something very wrong... in myself. I know I’m different, part of me wants to be able to do the things other people do, not to be bound by constant anxieties [...] like the fear people are always staring at me... that’s why I always wear these sunglasses, sunny or raining, even inside.”

[Guy]

This young adult’s description of his feelings, his appearance, his behaviour and other people’s responses to him is typical of the experience of *not quite fitting in* for many young adult participants. He feels different; he perceives himself to look normal but feels something to be ‘wrong’ within himself. He describes his constant anxiety and fear that affects his behaviour, for example, the wearing of dark glasses indoors and in all weather. In turn his behaviour affects how others perceive and respond to him, for example, staring at him. Such examples as this are presented throughout this chapter in order to present a case that for young adults *not quite*

fitting in is associated with them having a non-obvious disability whereby their apparent outward appearance of normality masks underlying differences of thought, perception and behaviour. This results in social expectations that do not match young adults' social understanding or their social skills of communication and interaction. The data suggests that non-obvious differences leave many young adults socially isolated and unable to access special services such as health and other social care services.

In the discussion of findings (chapter eight) a theoretical argument is developed to explain why young adults feel different and why they *do not quite fit in*. Furthermore a theoretical case is made to differentiate between the nature of *not quite fitting in* for people with Asperger's syndrome and others who may also experience feelings of 'not fitting in' whether as a result of disability, mental health problems or simply personality. The basis for this argument is rooted in the subjective experiences of young adult participants that are set out in this chapter. These *not quite fitting in* experiences are presented within the four interconnecting categories that together form the core category: how young adults feel, how they appear, how they behave and the reactions of others towards them.

5.3 How young adults feel about themselves

A common thread identified in the accounts of young adults was that of feeling different and of not fitting in. Such feelings were widely expressed across the data. For example,

"My basic problem is that I don't fit in."

[Richard]

"I've always felt different [...] like I'm the wrong bit in a jigsaw."

[Andrew]

"I don't fit in here... I feel like a stranger."

[Nick]

Some participants described the existence of these feelings from as far back in their lives as they could recall. For example,

"I just felt uncomfortable around people ... straight away I realised I was not right ... It was just a sort of vague uncomfortable feeling."

[Ben]

"I remember being aware that I was different for most of my life, my parents and teachers tried to get me to 'fit in' more ... to try to make friends ... to act normal."

[Guy]

Such feelings of not fitting in led, in some instances, to feelings of not belonging.

For example,

"I don't belong anywhere. I am completely alone and isolated in this ... this alien world."

[Thomas]

"I do not feel like I should have to belong to this group of people because we are family ... I don't fit in here. I feel like a stranger living amongst them."

[Nick]

Interestingly, whilst many young adults described feelings of wanting to fit in socially, a small number of young adults stated that they did not want to fit in, they actually wanted to be different. For example,

"I don't want to be a sheep. I want to be different. I need to be different. I can't be like the others ... I won't be made to be like them ... to follow others around blindly because that's what you are supposed to do ... I don't accept that philosophy of living."

[William]

"I do not subscribe to conformist society. I like being different ... I am proud to be different. All through my life people have been hammering me down ... trying to make me conform ... it doesn't work ... it just batters me ... but it doesn't make me into somebody else. I cannot change I am who I am ... why should I want to be anything else? I am proud to be different ... I don't want to be like others."

[Nick]

It seemed that these participants rejected the feeling that they should conform to the perceived expectations of others. Far from wanting to fit in they described wanting to be seen as different and of wanting others to accept them as different. Furthermore they perceived that they had no choice in this; they felt that they could not be anything but different. Furthermore they both drew attention to society's conformist expectations about how people should behave and stated that they rejected this philosophy for living. Even so, regardless of the desire to be 'different', they found the consequences difficult to live with. Both participants described feelings of loneliness and depression. For example,

"It can be terribly lonely ... I have nobody here to relate to ... nobody seems to understand ... everyone is so preoccupied with being the same [...] I did have 'a friend' once but she ended up shunning me ... other people can't cope with difference so they turn away from me."

[Nick]

It seems that despite wanting to be different others could not accept it, and participants felt lonely and isolated. Thus the desire to live outside social norms and be a 'separate self' appeared impossible to achieve. Equally, young adults who wanted to fit into their social context also seemed to find this impossible to achieve. For example,

"I look at other people walking around ... talking ... laughing ... finding everything so easy and I want to be them ... not this person."

[Sebastian]

"Everything I do that involves being with or talking to people is so much of an effort... I do wish I wasn't afflicted by this...I wish I could be more normal."

[Thomas]

In this sense the statement by the young adult participant [William] who stated he 'could be no other way' seems an accurate description of their predicament:

whether they wanted to fit or not, they could not achieve it. It seemed that regardless of young adults' best efforts of trying to fit in or not, they were unable to change the sense of being different. This appeared to be related to their sense of self in relation to others and many young adults seemed confused about who they were. It was not uncommon for young adults to ask of themselves "Who am I?" For example,

"I wonder sometimes who I am. Who is this person in here? Where is he? It's as if sometimes I am outside of my body looking at this guy thinking 'Who is he? What does he think of this or that'? It all feels so superficial ... I don't know who I am."

[Guy]

"I don't know who I am, 'who am I?' That's the hardest question 'Who am I?' I don't know who I am so how can I explain to you who I am? I'm in turmoil about this question. I wish I knew [...] I'm always looking at other people wishing I was them ... not this person ... whoever he is?"

[Sebastian]

Many young adults expressed such feelings of wishing they were somebody else and not knowing who they were. Other feelings that might be linked to this were of living with constant anxiety and depression. For example,

"Because it is an effort for me to even say ... say hello to someone I know walking past them ... or to talk to the man next door... to do basically anything that involves talking to people. It takes so much mental energy to do things that other people do so easily ... that's why I get so nervous ... I get worried I might say the wrong thing or... it's difficult to explain ... but I am a very anxious sort of person."

[Thomas]

"Nobody knows how difficult the everyday, ordinary things in life are for him. The effort required to speak to you now is so much more than for most people. It's little wonder he's so anxious all the time and suffers terribly from depression."

[Mary, mother of Philip]

From these participants it seems that the amount of effort required for young adults to interact socially in everyday encounters is quite considerable. Difficulties encountered with social interaction and social understanding generated high levels of anxiety, which further impeded them in everyday life. During the interview with some young adults, feelings of anxiety were clearly visible. For example,

‘Lisa was so very nervous, so much so that I wondered if I should be interviewing her at all and at one point offered to stop. Throughout the two-hour interview she sat physically shaking and only gave me fleeting eye contact. She firmly clutched and stared fixedly at a photograph of a famous bridge, which her father explained helped to calm her.’

[Interview memo 13/08/00]

In addition to the constant anxiety felt by many young adult participants, many also discussed feelings of depression. For instance,

“I go up and down a bit ... not too bad at the moment ... but there are times when the anxiety gets to me and I feel very depressed ... like I know I will always be like this and nothing and nobody can help me.”

[Guy]

Depression can be linked to an awareness of being different and feelings of hopelessness that there was nothing anyone could do to help. In the following excerpt the participant distinguishes Asperger’s syndrome from classic forms of Autism whereby people are believed to have less awareness of their differences,

“It [depression] seems par for the course that people with the high functioning ... the high end of Asperger’s ... all I can reason is if people have it severely they don’t realise there is a problem ... they are blissfully unaware but for us you realise there is something quite wrong ... something terribly wrong that you can’t really put your finger on it and it’s the awareness that’s the killer ... I think ... I guess that’s what causes the depression and self loathing.”

[Ben]

From this perspective it is the ‘awareness’ of difference that is a feature of ‘mild’ Asperger’s syndrome. This awareness is being described as harder to live with than

being unaware as for those with more 'severe' forms of Autism. Another participant illustrates this,

"Asperger's syndrome is not like autism ... it is a subdivision sure but in essence when you think about perception wise and the pain ... the real severity of the pain that the individuals will go through it is the opposite. I think that autistic people are in a world of their own ... they are oblivious to things that go on outside them and so they are contented with the way they are [...] I wish I was like that ... in terms of affliction ... in terms of the depths that you go to ... the emotional depths that you go to ... Asperger's is a lot more ... deadly."
[William]

These participants talked about the awareness of difference as being the 'killer' and linked this awareness to their feelings of depression and self-loathing. However, although many participants did demonstrate high levels of awareness about their own difficulties, this was not evident across all the data. This suggests there is a continuum of self-awareness amongst young adults with Asperger's syndrome synonymous with the continuum of autism, that is, from Asperger's syndrome through to severe autism.

At the lower end of self-awareness, one parent participant pondered over the advantages and disadvantages of her son's apparent unawareness of his differences,

"I don't know if he really knows that he is different from other people ... he never says [...] he seems oblivious to this and I really can't say... I don't know whether this is a good or bad thing. If he saw some of the things he did ... perhaps he would be able to fit in more. But maybe he would find life even more difficult if he knew and ... then ... perhaps he wouldn't have had any help at all?"

[Margaret, mother of Glen]

This mother recognised that her son's lack of awareness impacted on the way that he looked and acted, and she wondered if he might fit in better if he had greater awareness of his differences. However, she was not sure whether awareness was an

advantage or a disadvantage both in terms of how he would feel about himself and in the level of help and service provision offered. This suggests that there are costs and benefits associated with levels of greater and lesser self-awareness.

In summary, on examining how young adult participants 'feel' about themselves, it was found that feelings of not fitting in, of difference, and of not belonging were pervasive. Such feelings appeared to be linked to young adults' difficulties with finding a sense of 'self' and enduring feelings of anxiety, depression and self-dislike. This finding suggests that high self-awareness allows for a greater capacity to compensate for difficulties in conforming to social rules and looking normal. But, the effort required for this coupled with chronic anxiety and self-loathing led to the view that *"it's the awareness that's the killer"* [Ben]. On the other hand young adults with less awareness may not, as a consequence, develop learning strategies for 'covering up' their difficulties and may therefore look and behave more unusually than those with greater awareness. However, in return for their differences being more visible, some parents suggest that professional support may be offered more than for those with less obvious needs. The next category considers how participants perceived their appearance to themselves and others.

5.4 How young adults appear to others

This section describes the category of 'outward appearance' in contrast to the previous category that considered young adults' 'feelings' within themselves. However, there is overlap since appearance affects feelings and vice versa. In this category the dimension of outward appearance is described from 'looking normal' to 'looking different'. A tentative link is made between outward appearance and self-awareness discussed in the previous category.

5.4.1 Looking normal

On the whole, participants described themselves as ‘looking normal’, although there were some who appeared ‘odd’ in their appearance at the time of interview. However, most participants expressed a belief that it was the outward appearance of ‘looking normal’ that ‘covered up’ their underlying difficulties. For example,

“People don’t realise I’m autistic because they only see the normal looking exterior ... not the real Kate underneath ... they don’t see the problems I have.”

[Kate]

This young adult recognises that her disability is masked by her outward physical appearance of ‘looking normal’. Meanwhile others believe that ‘looking normal’ led to them being misunderstood throughout their lives. For example,

“Because I look normal people didn’t believe I was different ... I was always misunderstood at school and got some pretty rough treatment ... not just from the other kids but from teachers as well ... they didn’t understand [that] I didn’t understand.”

[Richard]

This belief is supported by some parents who highlighted that their son or daughter’s ‘normal looking’ appearance hid the true nature of their disability. For example,

“The trouble is he looks so normal that nobody sees he’s actually really disabled. I mean socially ... socially ... he’s really quite disabled.”

[Amanda, mother of Paul]

“Carl [is] a six foot three young man who looks perfectly normal ... he doesn’t look as though he has a handicap.”

[Carol, mother of Carl]

Thus parents contended that ‘looking normal’ had led to their son or daughter (and themselves) being misunderstood and unsupported. For example,

“For years he was totally misunderstood and labelled as an emotionally and behaviourally disturbed child [...] with inadequate parents [...] he never got any help at school ... neither did we.”

[Jenny, mother of Jack]

Such lack of support was highlighted by one parent who described the contrast between the professional assistance available to her son who has Down's syndrome, described as an 'obvious disability' and that for her second son with Asperger's syndrome. For example,

“I think it's such a different ball game from my other son ... he's got Down's syndrome ... from the moment he was born it was clear he would need help and support ... he's always had a social worker and to a large extent his life was mapped out from very early on ... now he's an adult he lives away from home in a supported adult placement ... he has his own semi independence ... whenever there are problems his social worker steps in ... and I think out of the two of them he is not the one that needs it the most.”

[Jill, mother of Martin]

Although some participants believed it was a disadvantage to have a non-obvious disability, some young adult participants saw 'looking normal' as advantageous. Not all young adult participants wanted others to know that they had a disability. From this perspective an outward appearance of normality assisted them in trying to fit in. In the following examples young adults' describe a number of strategies they used to conceal their differences from others. For example,

“I am careful about who I tell about Asperger's ... not everyone would understand, would they?”

[Thomas]

“I have a mental game ... I play at acting normal ... I study people ... copy words and phrases ... little actions ... that way I get by... people see me as just a bit shy or a bit eccentric. I prefer it that way.”

[Andrew]

“I want to fit in ... I know I'm different but I don't want to be seen that way. I try hard to make sure I look just right ... my clothes have to be right ... because ... to me it's very important not to stand out in a crowd.”

[Paul]

For these participants 'looking normal' was important as it helped them in trying to fit in. Throughout the period of data collection, on meeting young adults, most did appear as 'normal' to me and it was easy to understand what participants' were meaning in saying 'normal looking' appearances masked their differences. However, not all participants appeared as 'normal looking' as others, as discussed next.

5.4.2 Looking different

In contrast to many young adult participants who 'looked normal', two young adult participants looked somehow 'different'. Although this appearance of 'difference' is not easy to describe, one young adult's parents were able to illustrate how their son stood out. For example,

"There is no getting away from it Dean does look a bit geekish ... he always has and has suffered terribly from it ... picked on ... bullied... teased ... because of the way he looks. We used to try and shield him from it by choosing his clothes ... telling him what to wear but ... it's more than that ... he looks awkward ... he's never sure where to put his arms or what to do with his hands ... it's difficult to explain but he just looks a bit odd."

[Alex, father of Dean]

Thus, even 'looking different' was a difficult concept to explain. Interestingly, young adults who 'looked different' also seemed to be less aware of their outward appearance than other young adult participants. On interviewing these young adults I remarked on this in interview memos. For example,

'It is difficult to describe but Dean does appear 'odder' than the other young adults I've met. On meeting him he put out his left hand for me to shake which threw me a bit (a good example of a learnt social behaviour that isn't quite right or 'misses the mark'). He was wearing a brightly coloured woolly jumper on a hot sunny day and he appeared unaware that his appearance and behaviour was in any way unusual'

[Interview memo 02/09/00]

‘Richard seemed quite gauche, for example, awkward and uncoordinated in the way he looked and walked. He arrived clutching a plastic carrier bag and wearing clothes that made him look homeless. He didn’t seem to be aware that his appearance was a little strange for a young man in his twenties who lives with wealthy parents.’

[Interview memo 10/10/00]

On analysing the data, it seemed likely that self-awareness was linked to outward appearance. For example, the more self-aware young adults are the more likely they were to put thought and effort into their outward appearance and how they behaved than those with less awareness of ‘self’. This is illustrated in an analytic memo,

‘In comparing young adult participants I get the impression that those with the greater self-awareness are more likely to ‘look normal’ in the way they dress and the ways in which they behave and interact socially. This seems due to awareness that their looks have an impact on others. Awareness seems to affect the ability to modify appearance and behaviour.’

[Analytic memo 02/05/04]

Thus it seems that the issue of ‘looking normal’ is more complex than at first presented by both young adults and parents. As reflected on in a further memo,

‘Even those who did ‘look different’ had not received a childhood diagnosis of Asperger’s syndrome or special help in school. All participants, regardless of appearance, talked about having little formal help or support throughout their lives. Hence, ‘looking normal’ is not the only issue; people who are deaf look normal, children with chronic diseases often look normal. For these participants, this is about Asperger’s syndrome being complex, hard to understand and being difficult to identify – about having a non-obvious disability.’

[Analytic memo 02/05/04]

In summary, both young adult and parent participants appear to believe that ‘looking normal’ is a key feature of *not quite fitting in*. It appears that it is the non-obviousness of Asperger’s syndrome that underpins the experience of being misunderstood and unsupported and to a degree distinguishes the experience of

having Asperger's syndrome from more easily recognised and understood illnesses and chronic conditions such as Down's syndrome. However, there was variation in how 'normal looking' young adult participants were, with some 'looking different'. This is tentatively linked to differing levels of self-awareness, as similarly highlighted in the previous section with regard to awareness of difference and its impact on feelings. In consequence, the significance of 'looking normal' for young adults with Asperger's syndrome is more complex than simply their outward appearance; it is also linked to how they perceive themselves and how they behave.

5.5 How young adults behave

Within the accounts of both young adults and parent participants some 'curious' behaviours were described that did not quite fit with the 'normal looking' appearances of young adults. With regard to young adults' behaviours, there were a number of factors involved that merged together in forming the overall category 'behaviour'. The subcategories explain why young adults behaved in ways that did not seem to 'quite fit in'. As such, this section sets out these findings under the subheadings: 'being socially acceptable', 'avoiding social situations', and 'interests and routines'.

5.5.1 Being socially acceptable

One way in which many young adults attempt to become more socially acceptable is in trying to imitate or copy others. For example,

"It's like an act ... it's all an act ... pretending to be normal ... you want to be like them."

[Matthew]

"I watch other people ... how they behave ... speak. I learn whole phrases and sort of try and be able to... you know... get on better... socially. Another

way I do this is by watching TV and seeing how people behave. I copy what they have said ... how they say it ... how they approach someone. Things like that."

[Sebastian]

In trying to cope with feelings of not fitting in some young adult participants turned to substance misuse behaviour. On starting University at 18 years old, the following participant describes encountering a culture of 'social drinking', which took away any need for having the social skills that he felt he lacked. For example,

"Straight away when I had just turned eighteen I immediately started in Fresher's week ... like there is a whole social thing in drink. I was really, really awkward but I immediately found that when I drank it seemed to make things a lot easier [...] I found a group of people who were very heavy drinkers and I found that having a relationship was based pretty much on going out ...it wasn't so bad that socially my skills were not good because we were just going out to drink."

[Ben]

This participant had found a social group of young men who did not require him to have many social skills; he simply needed to join in with their heavy drinking binges. Likewise another participant found that alcohol and cannabis eased his social anxiety,

"Like a lot of people my age I experimented with drugs ... alcohol first then cannabis. I found it so much easier when I'd had a smoke ... people wanted to know me ... they seemed to find me interesting. I found it easier to be sociable and be amongst a group of guys my age."

[Guy]

Whilst alcohol and drugs may help many people other than those with Asperger's syndrome to fit in socially, both the above participants stated that the easing of their social awkwardness was only a transient benefit. To compensate they describe consuming more and more regardless of the time of the day or whether others were with them or not. This in turn led to their behaviour becoming more and more inappropriate and less acceptable to those around them. Interestingly, this strategy

had the longer-term effect of further excluding them from fitting in with the course of normal daily life and social friendships. As one illustrated,

“The trouble was I never knew when to stop ... I overdid it and ended up being even more alone ... I can get quite angry and people get a bit scared of me.”

[Guy]

Thus such behaviours could, in turn, lead to further aggravation of their social isolation. However, to some young adults the avoidance of social situations was preferable to the anxiety and stress of always trying to fit in.

5.5.2 Avoiding social situations

Not all young adults either wanted to or were able to behave in ways that made them more socially acceptable. Some young adults were not able to conform because they did not know how they should behave socially, and in turn their lack of understanding led to avoidance of others. Reflecting on his time at school, one young adult explained,

“Everything was so busy at school. Everyone seemed to know what they were doing. Not me ... I was always out of sync ... in the wrong place ... late for lessons. Break times were awful ... I would hide at break ... lock myself in a toilet or crawl underneath the temporary classrooms ... sometimes I would stay there all day just so that I didn’t have to feel so awkward ... the teachers thought I ran away because of the bullying. I was bullied but that’s not why ... I hid because I couldn’t bear not knowing what I was meant to be doing.”

[Martin]

In this instance he believed that teachers credited his behaviour at school to being bullied, which he saw was probably an obvious reason for his frequent disappearance. However, he afforded a different cause for his behaviour that revealed a more fundamental difficulty for him, and that is the constant state of confusion, always feeling ‘out of sync’ socially with his peers and doubting as to what he should be doing at any given time. His running away and hiding was based

on his need to escape from that which he could not understand. This motivation was not easily observed or easily understood by those around him such as teachers, peers etc. The behaviour of this participant was, therefore, based more on his lack of social understanding than on the perceived relationship with his peers. Another young adult described a similar behaviour of 'running away' from difficult social situations at school but in this case it was because he could not see the point of social 'chat',

"I remember one time ... I was a rower and we were rowing down the river and ... I just wanted to row and they said 'Let's stop off here on the island and have a chat' ... and I said 'Whoa ... I'm not having that'... So I jumped out of the boat and I swam across the river ... and I ran about three miles back to the boathouse in wet games clothes and right back to the school. That's just an example of ... to get away from these social situations ... I would do these crazy things."

[Andrew]

This participant described his need to get away from such social situations to such a degree that he perceived his behaviour as 'crazy', but for him this was preferable to the ordeal of conversing with his peers.

In contrast to behaviours that were based on not knowing how to behave, or simply not being able to conform, some non-conformist behaviour was consciously adopted. For example, one young man had purposely developed an upper class accent that was out of place with his working class family background. From his point of view this was because he wished to disassociate himself with his 'poor' family roots, despite the fact that he still lived with his mother and brother in a small flat in an impoverished urban district. In contrast to trying to fit in with his family and local community this had (intentionally) led him to stand out from his family and local community. As he explained,

"I hate people thinking I come from this family ... making judgements about me based on my parent's income and the sort of home that I live in ... I needed to change that. When I was a teenager I worked at changing my accent so people would see me as intelligent and not judge me on my family's merit but on my own."

[Nick]

Another consciously developed 'unusual behaviour' is further highlighted in the case of a 19-year-old participant who had adopted an odd walking stance whereby he walked bent forwards with his head held low and his chin resting on his chest. This seemed to be related to his fantasising about dressing up as an old man, hence for him, walking 'bent double' was a means of reducing anxiety about the social expectations that he perceived were placed upon him as an intelligent young man. As he explained,

"It would be so fine, so easy for me ... to dress up as an old man ... a very old man ... like 80 years old ... put one of those blazers on and a bowler hat or something ... white hair ... get a wig and wrinkles like a face mask so you do look old and bend over when I walk so people don't look at my face ... and then I would look at anyone I like because I am 80 and there are no expectations ... people disregard this ... they don't care about old people ... when I am walking next to an old person I feel safe ... I can look at these people ... I can relate to these people."

[William]

This participant believed that by behaving as an 'old man' people would then not look at his face. But he was still able to look at them and therefore he could avoid eye contact whilst still able to look at others. He believed that being old absolved people from social responsibility and from the expectation to behave in a sociable manner fitting for a 'good looking' young man. Thus walking 'bent-double' had significant meaning to him; it was his way of avoiding social contact when out in public and therefore helped reduce his anxiety about his perceived social ineptness.

For some young adults avoiding social contact and living a life of solitude was a positive choice and preferable to social contact. Thus social isolation was not always perceived negatively. For example,

"I am most content on my own ... I prefer being a solitude person ... that's fine with me ... a lot of people say to have a good time you go out and socialise right? Well for me that is a nightmare ... my good time ... to have a good time for me is to get away from that ... to get away from that situation ... I am totally the opposite ... it just puzzles me you know why they would want to do it ... it is suicide... it is personality suicide."

[William]

This young adult argues that in opposition to other people's need for social company he needs solitude. Thus, rather than so much wanting to be alone, young adults describe needing solitude as a means of survival. For example,

"I realise that I either solve how I can cope with life or accept I'm never going to have a career and never going to have a girlfriend or family ... maybe ... I just don't want it ... I just don't want any responsibility ... so I don't want to have to deal with society and that would be my way of saying I'm not interested anymore ... maybe this is my way of surviving."

[Ben]

Thus for some the ultimate avoidance of others was the act of suicide. Thoughts and acts of suicide were openly discussed by a number of young adult participants. This behaviour links back to young adults' feelings as already highlighted for example: awareness of difference, sense of self, anxiety, depression and self-loathing. Several young adult participants had actually contemplated or even attempted suicide. For example,

"I was fourteen the first time ... it all got too much ... I thought my life was hell ... wasn't worth living ... I took a load of my Mum's antidepressants and basically anything I could find."

[Andrew]

“Two or three suicide attempts over the years ... the first time I was about twenty-three ... that’s when I had to drop university the first time ... I saw this as a way out of the life I have ... it’s the ultimate opt out isn’t it?”

[Ben]

Therefore, for some, ‘opting out’ of life through suicide was a behaviour that was both contemplated and attempted.

5.5.3 Interests and routines

A tendency towards unusual interests and obsessive type routines was another feature of a number of young adults’ lives. This kind of behaviour took many and varied forms such as collecting various objects (magazines, videos, stamps), elaborate daily routines (personal hygiene, cleaning), sporting activities/games (martial arts, chess) and memorising facts (train time tables, football statistics). However, some of these behaviours seemed more ‘peculiar’ than others. For example, one participant reported a ritual of baking a cake on the same day of each week using the same ingredients,

“I bake a cake at home once a week ... every Wednesday...exactly the same cake at the same time on the same day, I do this once a week ... if I don’t I get a bit upset ... I worry things will go wrong for me ... so I have to do it.”

[Sebastian]

The same participant also described ‘having’ to go to a particular nightclub every Friday night, alone. When asked why, he replied,

“I don’t know sometimes to torture myself really ... I don’t know... I’m there in the club on my own aren’t I? You know... and everybody else seems to be with their friends and having a good time ... I just don’t know why I do these things.”

[Sebastian]

Another participant talked about his liking for watching women urinate and he felt fortunate because his girlfriend allowed him to watch her.

Turning to another example, one participant expressed her love of a particularly famous bridge. As a very anxious young woman she found the bridge reassuring and calming, and carrying a photo of the bridge around with her helped ease her anxiety. Although three hours' drive, her parents would regularly take her there as a treat, and she would spend hours gazing at it. Another female participant described her obsessive type need to check car tax discs to ensure that drivers had legally taxed their cars. She would on any given opportunity wait for and approach offending drivers to tell them they had broken the law and if she discovered an out of date tax disc she would inform the police or if she could find one, a traffic warden. This obsessional behaviour is illustrated in the next excerpt,

"I have a bit of a thing about cars being taxed ... when I'm walking along I will check to see if the cars parked have their tax discs ... if they are out of date I always report it to the police or a traffic warden ... if the driver is around ... and sometimes I wait for hours for them to come back ... I tell them ... it can get me into trouble I know ... but it's not me who's breaking the law."

[Kate]

This participant was aware that by telling drivers that their car tax was out of date could cause her trouble, but she seemed to have little sense of the actual impact her behaviour might have on others, or of the vulnerable position into which she was putting herself. She viewed her behaviour as a matter of fact. In her view this was the law and people should be told if they are breaking it. Whilst it could be argued that many people would share this view of the law, it would be considered somewhat unusual for them to react in the same manner. It is the participant's obsessive type behaviour and limited understanding of the potential consequences for her that set her actions apart from other people, and in turn her behaviour impinges on how others react to her.

In summary of the behaviour of young adults, a range of *not quite fitting in* behaviours were described by participants, which can be related to trying to appear socially acceptable, avoiding social situations, and the development of obsessive behaviour. In turn, such behaviours affect how others perceive them and react to them.

5.6 How Others React

This final category, 'how others react', together with young adults' feelings, appearance and behaviour forms the core category *not quite fitting in*. This category is based on the perceptions of young adult and parent participants as to how others respond to them, rather than data from others. Thus this section describes participants' perceptions of how others react to the apparent mismatch between young adults 'looking normal' and their *not quite fitting in* behaviours. In analysing the data there were a number of dimensions to others' reactions, which most commonly involved how others responded to young adult participants' difficulties in social interaction. In some social context young adults did find acceptance but most commonly they experienced being rejected and bullied by others, mislabelled, accused of pretence, and often forced into doing things that they found very difficult.

5.6.1 Being accepted by others

Some participants described instances when others were accepting of them. This was usually because they involved social relationships that did not require many social skills. For example,

"I formed a friendship with these guys who were really interested in the sciences ... there were three of us and basically would just talk facts ... we didn't really take part in the social part of the school we would just sit and chat away about science and physics."

[Ben]

"Alcohol and drugs helped me to be more social but relationships were not at all reliant on communication skills ... it was all about going out and getting drunk or stoned."

[Guy]

Such examples of being accepted by others were not frequently recounted. Acceptance by others (apart from parents) seemed to be related to others not judging them in relation to their ability to interact socially. Thus in the first example, the three friends shared a common interest in social science and none of them appeared to have an interest in 'being sociable', and in the latter example, the expectations of the social group was on getting drunk or high on drugs. Neither of these examples required good social skills, just a willingness to join in with the culture.

5.6.2 Rejection and bullying by others

More commonly young adults talked about being rejected and bullied by others.

For example,

"People seem to avoid me ... I get very lonely at times ... kids around here laugh at me ... and my neighbours aren't very friendly to me."

[Dean]

"It can be terribly lonely ... I have nobody here to relate to ... nobody seems to understand ... I did have one friend once or I thought I did but she turned on me."

[Andrew]

Having few close friendships and seeming rejection by others was a recurrent theme in young adults' life accounts. In particular, there were many cited instances of bullying by others. For example,

"At school I was always teased by the other children ... they would call me names ... throw stones ... steal my bag or my clothes after games."

[Andrew]

"Five girls followed me about ... calling names ... pushing me ... pulling my hair. It's because I was odd ... I always felt alone and never had any real friends."

[Rachel]

Furthermore, rejection and bullying did not end at school but for some persisted into adulthood. For example,

"He was doing work for [Computer Company] and he'd been doing it for a long time and very satisfactorily ... he always finished his work and I believe he's a good accurate worker. Some woman in the office didn't like his face or obviously didn't like something about him and she made life uncomfortable after a few days and said he wasn't working as fast as he should ... which I could never ever believe ... so one lunchtime he came home ... he said he felt ill and he didn't go back."

[Mary, mother of Philip]

"I thought that it would stop at College ... that everyone is more mature but in some ways it's much harder ... there's this one girl ... she keeps accusing me of things ... of following her ... harassing her and stuff like that ... it's not true ... I think she's trying to get me kicked out."

[Daniel]

5.6.3 Mislabeledled by others

One consequence of having a non-obvious disability is of others making judgments about young adults' behaviour based on their own beliefs and experiences of how people should interact and behave, rather than such judgements taking into account the disability. For example,

“They (other people) don’t see the problems I have in understanding what’s going on around me ... in processing information and in reacting according to society’s expectations of how people should behave ... so if I say something not quite right or act in a funny way that’s maybe a bit inappropriate they think I’m rude or badly behaved.”

[Kate]

Thus one way that others were perceived as reacting was through pejorative labelling. Some young adults saw themselves as being considered by others as badly behaved, naughty, rude, arrogant, or disobedient. Linked to these mistaken impressions are unrealistic expectations.

5.6.4 Unrealistic expectations of others

In another example of being misunderstood the following participant links other people’s wrong impressions and expectations of him,

“I cannot always explain myself too well and people get wrong impressions of me. I’ve been told I can be rude and arrogant ... a lot of the time I just don’t understand what other people are expecting from me.”

[Thomas]

Similarly, a number of parent participants talked about times when they had found it difficult to understand their son or daughter’s behaviour,

“There has been so many times when I have questioned ‘Why does he do that?’”

[Peter, father of Tim]

In the analysis of data this led to the question,

‘If parents find the behaviour difficult to understand how much more difficult it must be for others who are less familiar with these young adults’ ways?’

[Analytic memo 3/12/04]

Because some young adults’ behaviour was difficult to understand, it is unsurprising that other people might have trouble in understanding the reason for

behaviour that did *not quite fit in*. An example of this is the case of the participant who found reassurance in walking 'bent double'. In this instance, although the young adult understood his behaviour, his mother did not,

"He'd been behaving in the most bizarre way and been walking bent-double and you'd say, 'For goodness sake don't do that or don't be so silly' ... Why does he do that?"

[Sarah, mother of William]

5.6.5 Misbelieved by others

Some participants describe how others did not believe that they were in any way different from others. For example,

"I was often told that I wasn't really different I was just pretending to be different ... but I knew I was different ... In fact I was pretending not to be different ... I suppose that's the irony... people didn't believe I was different and I didn't want to be seen as different but then I'd get into trouble for being deliberately disobedient!"

[Richard]

This participant described the irony of being accused of pretending to be different when he felt he was pretending to be normal. As a result of being seen as pretending to be different others were minimising the problems that young adults experienced and there was a risk they could be forced into doing things that they found very difficult.

5.6.6 Forced to conform to others

Some young adults suggested that throughout their lives other people had tried to force them to fit in. For example,

"My parents ... my teachers tried to get me to fit in more ... to try to make friends ... to act normal."

[Guy]

“They [others] should stop trying to turn me into a cog ... it won’t work ... I won’t be moulded in that way.”

[Nick]

In the next example, one father saw that other people, including himself, had tried for a long time to make his son conform. He questioned the impact that this ‘forcing’ had had on his son,

“All his life people have been trying to force him to conform ... for a long time I did ... when he was little he would get very upset if we didn’t drive a certain way to school ... I went out of my way to change the route ... I thought he needed to learn there was more than one way to school ... be more flexible ... I didn’t know what I was doing to him. You can’t force a square peg in a round hole.”

[David, father of Luke]

This father regretted his insistence on trying to force his son to be more flexible and he worried about the effects on his son of trying to make him to fit in. In another example, a young adult participant describes how his employers had tried to force him to meet their expectations of his potential, they wanted him to be involved in a more demanding research and development role within the company, whereas he wanted to remain in his lowly position of sterilizing equipment as he enjoyed the routine and structure of the tasks this involved. He describes how his employers could not understand his point of view, which resulted in him resigning,

“I worked in a very challenging environment [...] in a pharmaceutical company [...] they wouldn’t let me do the job I wanted ... it was one of the lowest positions in the company [...] I said ‘this is what I want to do ... I like this job’ ... they said ‘No, we’re afraid we won’t give it to you, you’re too’ ... basically saying you should be working in research and development ... I couldn’t make it clear to them I didn’t want that stress ... I wanted something that had a similar structure everyday and I really did enjoy it and I was on my own a lot of the time and I didn’t get it. Soon after that [...] I just packed it in one day.”

[Ben]

In summary, the perceived reaction of others towards young adults is one of misunderstanding. Although there were a few examples of young adults being

accepted by others in some social contexts, this was related to circumstances not necessitating social skills. More commonly young adults felt others rejected and bullied them. Participants believe that others have expectations about how they should behave and others did not believe they had genuine difficulties and consequently tried to force them to conform and to fit in.

5.7 Summary of chapter

In this chapter, the core emerging category *not quite fitting in* has been presented in relation to the interlinking categories of how young adults' feel, appear, and behave, and the reactions of others to them. The key components of *not quite fitting in* are related to looking normal alongside the existence of the subjective feeling of being different, and behaving in ways that others perceive as somehow curious or unusual.

The phenomena of *not quite fitting in* is described as encompassing a wide degree of variation with a few young adult participants being more obviously odd looking than others. Some young adult participants appeared to have a lesser degree of awareness of their differences than most and a tentative link between self-awareness and appearance arose from the findings. It seemed from the data that the more aware young adults are of their differences the more likely they are to negate these differences by modifying their appearance and behaviour to match their perception of how others expect them to behave. Across the data a number of *not quite fitting in* behaviours were also apparent. Most commonly behaviour involved young adults trying to make themselves more socially acceptable, avoiding social contact and having intense interests and routines that tended to be self-absorbing and often did not involve sharing the interest with others. Some young adults seemed to have

little sense of the vulnerable position that their behaviours sometimes placed them into, which suggests that in addition to being misunderstood by others, that young adults' also lack understanding of others. Such difficulty in social relationships was recognised by Hans Asperger as: '*the fundamental disorder of autistic individuals is the limitation of their social relationships*' (Asperger 1944:77). Thus the relationship between young adults' sense of self in relation to others appeared to be a central concern, these findings will be discussed further in chapter eight having been analysed through the theoretical framework of symbolic interactionism and from which some hypothetical explanations emerged and implications for health care practitioners will be drawn. However, the next chapter will focus on the *not quite fitting in* experiences of parents as 'hidden' or 'covert' carers living with an adult son or daughter with Asperger's syndrome.

Chapter six

Findings: parents

6.1 Introduction

In this chapter, the findings in relation to *parent* participants are presented. Twenty-three parents, 17 mothers and 6 fathers, participated in the study, all of whom played a central role in the life of their adult son or daughter with Asperger's syndrome. The data considered in this chapter comes from parents' accounts alone. This is because the young adults' accounts focused only upon themselves and therefore did not add anything to the parents' data. This chapter will begin by outlining the core category of *not quite fitting in* as experienced by parents. This differs from the experience of young adults but also builds upon the findings presented in relation to young adults set out in the previous chapter, in that Asperger's syndrome is a non-obvious disability with non-obvious needs, and these non-obvious needs have a direct impact upon parents' lives. Differing dimensions of *not quite fitting in* will be considered and linked to the four categories set out as the following subheadings: 'On still being a parent', 'On the things that parents do', 'On perceived responses of others' and the 'On costs and benefits to parents'. As many of the issues interlink across the different categories, there will be some overlap. Where this occurs it will be a different dimension of the category that is being explained.

6.2 The core category - *not quite fitting in*

The findings set out in this section will be presented in relation to the *not quite fitting in* experiences of parents, and will be contrasted to the *not quite fitting in* phenomenon experienced by young adults. Key features for parents – being a parent and carer, covert and psychological caring, family isolation, and the health and social costs for parents – form the core category and will be considered

throughout the chapter. This section provides an overview of the core category and in particular the dimensions of *not quite fitting in* for parents.

6.2.1 Dimensions of not quite fitting in

This section will introduce the dimensions of *not quite fitting in*, firstly how the phenomenon arises for parents, followed by four competing dimensions of *not quite fitting in* – ‘letting go’ versus ‘holding on’, and ‘normalising’ versus ‘differentiation’.

Parents seemed to acquire their *not quite fitting in* experiences by virtue of ‘being a parent’ to a son or daughter with Asperger’s syndrome. This is unlike young adults who experienced *not quite fitting in* as a consequence of their own innate attributes. Thus, the essence of *not quite fitting in* for parents differs qualitatively from the experiences of young adults, while at the same time it is inherently linked to being the parent of a young adult with Asperger’s syndrome. Hence, just as young adult participants *did not quite fit in* to their social context and to social assumptions about everyday behaviour and social interaction, parent participants *did not quite fit in* to their own social context or to social expectations about the role of parents when a child reaches adulthood. The phenomenon of *not quite fitting in* for parents appeared to have a number of different and sometimes competing dimensions. In particular there appeared to be issues for parents in knowing when or how to ‘let go’ or to ‘hold on’ to their adult child in terms of their role and responsibilities towards them. This appeared to be linked to the dimensions of normalising versus differentiation. It appeared that parent participants neither *quite fitted* the expected role of parents in ‘letting go’ of their children as they reached adulthood. However, nor did they *quite fit* what they perceived to be a ‘parent carer’, akin to parents of

children with overt disabilities needing continuing care throughout adulthood. For example, the next excerpt describes the experience of a mother with an older son with Down's syndrome,

"With Adam the transition from child to adult was smooth ... it was planned and well thought out ... his needs and ours were taken into consideration ... we were able to let go and he was able to move on ... we can't let go of Martin ... there is no one to stop him from falling."

[Jill, mother of Martin]

Thus parents felt unable to 'let go' of their adult children, but at the same time they were reporting that they also wanted to help their son or daughter to lead lives less dependent upon them. Secondly, parents wanted others to recognise and help them to facilitate their son or daughter in 'moving on' in their lives, for example, by helping them to achieve greater independence from them. However, the functions that parents performed were often carried out covertly and thus the roles parents took on were not obvious to others and therefore not easily recognisable. Parents kept their 'looking after' functions hidden in the hope that this would help their son or daughter to feel normal. Thirdly, parents believed that their son or daughter could not 'survive' socially without their input because there was nobody else who understood them and there were no services available to support them. Thus parents were faced with the dilemma of both wanting their son or daughter's disability to be more obvious (to enable access to health and social care services) and of wanting to 'normalise' the young adult's situation by minimising their difficulties and by keeping their own caring role hidden. Thus the dimensions of *not quite fitting in* for parents include the tensions between 'letting go and holding on' and between 'normalising and differentiating'.

In this section, some of the dimensions and issues facing parents have been introduced and will be explored further in this chapter. The next section considers the broad issue of being a parent to a young adult with Asperger's syndrome.

6.3 On still being a parent

A key dimension to being a parent to a young adult with Asperger's syndrome was the 'continuous' role of parenting a child that never 'quite' came to an end, as parents' son or daughter 'never quite put two feet on the ground' to reach a place of living independent lives but remained to varying degrees dependent on their parents for food, shelter, financial assistance, psychological support, and companionship. A further dimension of this ongoing role includes that of *not quite* being a parent to a 'typical' adult child and *not quite fitting* the role of a 'parent carer' to a child with an obvious learning or physical disability. Linked to this are also the issues of 'letting go' versus 'holding on', as previously mentioned.

6.3.1 Being an 'untypical' parent

One aspect of being an 'untypical' parent that parents talked about was that of *not quite fitting in* to either a 'normal' parent role (whereby the adult child becomes increasingly less reliant upon the parents) or a traditional carer role of looking after an adult child with an obvious disability. For example,

"My older son has severe learning disabilities and all through his life we have been supported in caring for him ... and now he lives in a supported lodgings scheme and has his own social worker ... we can be normal parents ... be there when he wants us but not have the burden of his care thrust upon us."

[Jill, mother of Martin]

Interestingly, this parent felt she and her husband could be ‘normal’ parents to their son with Down’s syndrome and not to their son with Asperger’s syndrome. This appeared to be linked to the son with Down’s syndrome living a life ‘independently’ of them as his parents, and them consequently not being responsible for the ongoing ‘burden’ of his care. Whereas the son with Asperger’s syndrome received no formal support and continued to be dependent on them in adulthood. This parent was arguing that not only were the needs of her son with Asperger’s syndrome unrecognised and unmet by others, but so was her role as a ‘parent carer’ in comparison to being a parent of an adult child with obvious physical and learning disabilities. Thus a major consequence of having a son or daughter with a non-obvious disability and non-obvious needs is the prospect that their adult child may remain dependent on them indefinitely. This also created anxiety for many parents who expressed concern about what would happen when they were no longer capable of caring for their son or daughter. For example,

“I worry awfully about what happens when we die. My husband’s 76, I’m 65, um, Philip’s got to cope with this house, he can’t, he couldn’t. Not only that, I don’t think he can live on his own for a long time.”

[Mary, mother of Philip]

Thus parents were being faced with a dilemma of ‘letting go’ or ‘holding on’ and not knowing which was really in their *adult child’s* best interests.

6.3.2 ‘Letting go’ versus ‘holding on’

For parent participants, the difficulty in ‘being a parent’ to their son or daughter with Asperger’s syndrome seemed very much to be about their roles and responsibilities that extended into adulthood. This was over and above what might ‘normally’ be expected of parents with adult children. As has already been

highlighted, parents described being faced with a dilemma of not knowing how to 'let go' causing them to 'hold on' for fear their son or daughter could not cope alone. For example,

"I think empty nest syndrome is always a problem. As your children grow older they go away and lead their own lives and so that the mother and perhaps the father to a lesser extent is sad then ... I don't have an empty nest ... I still have Carl very much in the nest."

[Carol, mother of Carl]

In this example, not 'letting go' was seen as a positive aspect of parenting a son with Asperger's syndrome. This mother recognised how difficult it was 'letting go' and allowing any child to live a life independent of them, thus a part of her felt glad that she did not have to experience this. However, whilst this mother valued her son's company, and was glad not to have to 'let go' of him, she also recognised that her son's prolonged dependency inhibited her and her husband from 'moving on' with their own lives. As illustrated in this excerpt,

"Once your children have grown up and gone away then [...] mum and dad are meant to find themselves again [...] then go on to another phase of your marriage [...] and in fact we haven't got onto that phase."

[Carol, mother of Carl]

However, for most parents the reality was that they could not 'let go' because they believed that their son or daughter could not survive without support, and there was nobody else who would do this. For example,

"It's always left up to us as parents because who else will do it?"

[David, father of Luke]

"And you want people to be integrated into society and enjoy the mainstream activities but it does have to be managed [...] and you know it is the parents whenever they are there because it is nobody else who will do it."

[Carol, mother of Carl]

Thus some parents felt unable to 'let go' by reducing the ways in which they 'managed' young adults' lives because they believed their son or daughter would not 'survive' emotionally, practically or financially. In the absence of recognition of their predicament and support to help their son or daughter achieve greater independence, parents felt their only option was to continue to 'hold on' to their caring roles and responsibilities.

6.4 On the things parents do

This category considers parents' descriptions of their roles and responsibilities towards their son or daughter that appeared to be largely 'covert' in nature. As their children entered adulthood, parents seemed to unquestionably subsume some forms of 'caring' that both resembled and differed from perceived conventional forms of caregiving. They were carrying out common caring tasks such as providing food, shelter and managing finances, but overall, theirs was more 'hands off' caring that involved functions such as 'psychological watching over', 'structuring and managing', providing 'companionship', and 'moulding' their own lives around their son or daughter. Some parents also described constantly seeking to create opportunities for their adult son in terms of socialising, further education, employment, and leisure activities. Overall, these 'carer' type actions seemed to be carried out without the explicit knowledge of the young adults, thus they had a 'covert' quality. Even where young adults recognised some aspects of their parents' roles in their lives, they seemed oblivious to the extent of their parents' 'looking after' role.

6.4.1 Psychological watching over

The first aspect of ‘covert caring’ is the sense of parents ‘psychologically watching over’ their adult son or daughter. In the next example, a father and mother discuss this together,

“It’s not that he needs physically looking after but it is a 24hour psychological watching over.” [Peter]

“It’s like he’s still a young teenager and you’re trying to allow them freedom and encourage independence but also trying to keep them safe and it’s a difficult balance with Tim.” [Fran]

“And he’s 26 now and still in the teenage phase.” [Peter]
[Peter and Fran, parents of Tim]

In this example, the point is being made that parents are not providing 24 hour physical care but there is a continuous level of psychological supervision taking place. This is being likened to parenting teenagers but extended beyond that which may normally be expected. Many parents viewed their son or daughter as ‘socially’ immature for their chronological age and therefore perceived them as vulnerable to risks such as being out alone and not recognising danger ‘signals’ from others. For example,

“He’s meant to be an adult but in many ways he is still a child, very immature and innocent and just as vulnerable ... he is very trusting and can’t see danger.”

[Claire, mother of James]

This ‘watching over’ function was not a literal ‘watching’ but involved parents thinking ahead or second guessing what their son or daughter may encounter in any given day, and thinking about how they might cope and how others might be responding to them. Parents would try to avert problems by either preparing their son or daughter for any possible eventualities or by preparing others to be sensitive

towards them. Much of the psychological work of parents appeared to take place without very much awareness by their sons and daughters that this was happening. Thus this implied a level of 'covert'ness' to these activities. For example,

"He doesn't know what we do for him ... it's a case of thinking ahead and anticipating what might happen for him... this can be a simple level ... like making sure he knows where he's going ... what bus to take ... he's got enough money ... and more complex ... what to do if the bus doesn't turn up or how to react if he meets someone he knows."

[Mark, father of Richard]

Thus 'psychological watching over' was being carried out without young adults knowledge and varied in the levels of complexity. Such forms of psychological watching over can be linked to the actions of 'structuring and managing' young adults' everyday lives.

6.4.2 Structuring and managing

'Structuring and managing' young adult lives was another way in which parents cared for their son or daughter in unseen or 'covert' ways. For example,

"You have to manage that person's life really although a lot of it is hands off rather than hands on but somebody has to set out a structure for their lives."

[Carol, mother of Carl]

Like, 'psychological watching over', 'structuring and managing' involved a 'hands off' rather than 'hands on' approach to caring for young adults, however this aspect involves some action. In a further example, the parent describes 'structuring' her son's everyday life,

"Philip couldn't cope on his own ... he can cook and wash ... but bills ... knowing what to do if he was unwell ... knowing how to structure his day ... know who is genuine and who would want to take advantage of him [...] He doesn't need everything doing for him but he does need guiding."

[Mary, mother of Philip]

Thus this aspect is the next step in ‘psychological watching over’. It involves some action by parents. This could be arranging activities, social engagements, educational courses, and for some finding them appropriate employment. Another aspect was in providing unseen ‘safeguards’ to try to prevent young adults from making social gaffes or getting themselves inadvertently into trouble. For example,

“He likes to go to the local primary school fayre which is a worry ... even though he’s harmless others might not see him like that and wonder why he goes ... I’ve spoken to the headteacher... I’ve made a point of doing that [...] so you just have to put little safeguards in place to avoid a difficult situation.”

[Carol, mother of Carl]

This mother approached the headteacher to inform her of the situation and gain her permission in order to pre-empt any potential problems of her son attending a primary school fayre by himself, rather than to stop him from doing something he enjoyed and miss the opportunity to mix amongst other people. However, this was done without her son’s knowledge and could be seen as morally questionable since this action involved telling others about her son without his knowledge or permission. In taking this course of action she was making a complex choice between allowing her adult son to act freely, to explain to him why he should not visit the school fayre (and remove this enjoyment from him), or to take the risk of approaching the headteacher in the hope that she would understand and allow her son to attend the fayre and, she hoped, ‘look out’ for him in a considerate way.

6.4.3 Moulding around young adults

In this section the category ‘parent moulding’ will be described. This relates to parents ‘moulding’ their lives around young adults’ lives. It appeared that many parents had put aside many of their own personal needs, desires and ambitions to

encompass their son or daughter's needs. In the previous chapter it was noted in the accounts of young adults that they were all consumed by themselves and their own thoughts and feelings, whereas their parents' lives seemed inextricably bound with that of their son or daughter. For example,

"I live with him rather than him with me, it wouldn't work any other way ... you see he can't adapt like most of us do ... and so I have to adapt to him ... my life is moulded around his rather than him to me."

[Marie, mother of Robert]

Many parents viewed adapting or 'moulding' their lives around the young adults as necessary. They believed they had no choice; this was the only way to encompass them into the family because they said their son or daughter had difficulty in adapting to them or to ever changing routines. The next excerpt is illustrative of how one family's whole way of living had been and continued to be moulded around their son,

"My husband used to work away and stay away all week ... well he is retired now but we still keep to the routine ... he comes home at the weekends ... Robert couldn't cope with him being here all the time ... and I dare say he wouldn't cope with Robert either."

[Marie, mother of Robert]

In this case a family routine that had begun in childhood had continued into adulthood with no sense that this would ever change. Thus, this is an example of parents being unable to move on with their own lives and develop separate experiences and separate identities. Another example of parents putting young adults' needs and desires above their own was the way in which they talked about their own lives during the interview process for the current study. Parents' accounts did not separate their own experiences from those of the young adults, even when prompted to talk about their own feelings, emotions, hopes and ambitions. Parents'

talk seemed inextricably bound to their son or daughter's well-being. This was in stark contrast to young adults' accounts that were almost entirely centred on themselves, they barely mentioned their parents and, on the rare occasion when they did, they tended to lack regard for their parents' thoughts or feelings within the context of their dialogue.

6.4.4 Providing companionship and social networks

Many parents provided companionship to compensate for the absence of young adults' friendships and social networks. For example,

"He doesn't go out alone anywhere ... he doesn't have any friends ... only us and his sister ... he is always at home with us."

[Fran, mother of Tim]

Some parents appeared to go to extraordinary lengths to maintain and protect the young adults as well as help them develop personally and socially. One mother described how she attended evening classes with her son as a weekly 'social' activity for him as well as to help him to gain a sense of achievement. She had also made links with his work place and worked tirelessly without his knowledge to help his employers and colleagues understand him. She created a group of friends with other parents and their adult children with Asperger's syndrome to swim and have a meal once a week; this became part of their weekly routine. In an analytic memo I remark on the extent of this mother's role,

'Carol is an example of a mother working continuously to put in place unseen structures, opportunities and safeguards for her son, helping to enable him to live a safe and fulfilling life. Not all of the parents had the time, energy or inclination to go to such lengths but it seemed remarkable just how well so many parents understood their son or daughter and the extent to which they do try to protect, nurture and develop young adults.'

[Analytic memo 03/04/04]

Thus, some parents take on a companionship role for some young adults. This was not always the case as some young adults preferred not to spend time with their parents. But whether physically present or not, parents seemed to be available for young adults at any time of the day or night and in their own mind were 'psychologically watching over' their son or daughter.

6.5 On perceived responses of others

In this section, parents' perceptions of others' responses to them as parents and as carers are discussed. In analysing the parent data there was an overwhelming sense by parents that nobody understood them or their son or daughter. It seemed that over the years parents had experienced feelings that professionals had never listened to them. They also commonly expressed feelings of being blamed by others. However, a major difficulty for parents in highlighting the needs of their son or daughter to others was related to the issue 'normalising and differentiating'. It is this dilemma that will first be explored.

6.5.1 Lack of awareness in others

Parents discussed a general lack of awareness amongst both professional and lay others about Asperger's syndrome. Some parents recognised this had been exacerbated by their covert handling of their son or daughter's difficulties. For example,

"The trouble is we hid it so bloody well that nobody noticed."

[Amanda, mother of Paul]

Some parents acknowledged that they were stuck between wanting their son or daughter to feel normal and between making others more aware by telling of their difficulties. This relates to the issue of normalising versus differentiating. For example,

“We’re caught between wanting him to feel normal and wanting recognition for his needs ... do we tell people he has a disability or help him to integrate by improving his social awareness and skills of interaction?”

[Peter, father of Tim]

In other words, parents both wanted to minimise their son or daughter’s feelings of being different by keeping others unaware but they also wanted them to be able to integrate better. Thus they were unsure whether awareness in others was helpful or not. Nevertheless, many parents wanted formal help for their son or daughter to be able to ‘move on’ in terms of being more independent. For example,

“On the one hand I want others to understand what his difficulties are and to address those difficulties and be helped to move on with his life [...] but I don’t want him to be stigmatised or rejected by others ... to make others fearful.”

[Claire, mother of James]

The conflict therefore is between highlighting young adults’ unseen difficulties and keeping them discrete by parents ‘covertly’ managing young adults’ lives themselves. However, in many cases parent participants also felt that they had little choice in this. There was no point in telling others because in their view there was no appropriate help or service provision available. For example,

“Who else is going to look after him? It’s always left up to us as parents because there is nobody else who will do it ... it’s us who have to pick up the pieces when things go wrong.”

[David, father of Luke]

Even when some young adults had received formal help, parents were sceptical, and some scathing, about professionals' knowledge and understanding of Asperger's syndrome and of the role of parents. For example,

"I want to start by saying I have no faith in doctors, psychiatrists, social workers, so called specialists ... because we have had no help ... zilch [...] the system has destroyed us as a family ... because nobody understood Asperger's."

[Margaret, mother of Glen]

In another example, on accompanying her son to an appointment with a psychiatrist one mother found it was she, the parent, who was seen as the patient,

"This psychiatrist [...] said he would see me for six weeks to support me because I was getting a bit fraught about it ... so he did ... but he came up with a lot of rubbish ... he was saying maybe it's because my husband wasn't originally English ... he comes from Croatia ... maybe it was because my husband was eleven years older than me ... he came up with a lot of things that were nothing to do with our problems and absolutely no help to either of us."

[Mary, mother of Philip]

Thus parents felt themselves to be in a difficult position. They were unsure of whether or not asking for help would actually help them or their son or daughter. They did not want to unnecessarily 'differentiate' their son or daughter by telling others for fear of exacerbating their feelings of being different. But, even when parents wanted formal help they perceived there to be a lack of awareness about Asperger's syndrome amongst professionals and a lack of appropriate resources available to them.

6.5.2 Not being listened to

Parent participants gave many examples whereby professionals, notably teachers, doctors, nurses and social workers, had not listened to them over the years. For example,

“People were talking about him in meetings a lot since he was the age of six but they wouldn’t listen to me ... not one of them listened to what I had to say.”

[Margaret, mother of Glen]

Furthermore, parents complained that whilst nobody listened to them, they were always expected to listen to the ‘professionals’. For example,

“Nobody ever listened to us but we were expected to listen to them catalogue his daily misdemeanours.”

[Alex, father of Dean]

Not being listened to or included was something that parents had found became more of a problem as their child reached adulthood. For example,

“Parents aren’t kept informed of anything ... once he turned 18 he is seen as an adult and we are not taken into consideration yet we are always there to pick the pieces up and they know it.”

[Alex, father of Dean]

One father talked about an incident when his son had been admitted to a psychiatric ward from a day centre that he was attending after becoming aggressive towards a member of staff. The staff had not called his parents to inform them of what had happened. The father described how later that day they had received an indignant telephone call from a ward sister saying their son was there and that he didn’t have any pyjamas or toothbrush or anything. Thus parents felt that on top of their own indignity of not being listened to by professionals, they also felt excluded from any planning and provision of care. However, parents also reported that they felt themselves to be recognised as important only when it suited others, and they gave examples of professionals paradoxically expecting parents to be available and

willing to 'pick up the pieces' in the absence of other forms of support, yet not being included in assessments or planning stages of care provision.

Many parent participants felt that they knew their son or daughter best but that this was not valued by others, but also, others expected parents to be available when needed. However, parents themselves felt that professionals were not available to them when they needed someone to turn to. For example,

"It is very hard not even having anyone to turn to when you need help ... our GP is a good man but he doesn't understand the problems ... the psychiatrist treated the depression and then discharged him ... the community psychiatric nurse said he didn't have severe mental health problems and discharged him ... social services don't want to know... there is just no one to turn to."

[Jenny, mother of Jack]

With no professionals to turn to, parents often felt left alone to deal with any problems and felt they were unsupported in coping with their son or daughter's emotional outbursts or distress.

6.5.3 Being judged by others

Being judged as being the cause of their son or daughter's problems was a common feeling amongst parents. Judgements about their parenting skills, their own mental health, and questions of abuse were all common experiences amongst participants. For example,

"After twelve years of school ... hundreds of meetings and one permanent exclusion I'm so full of anger ... if just one of the people I went to for advice had suggested that his behaviour wasn't due to poor parenting ... family breakdown or secret abuse at home and had mentioned Asperger's to me ... life might have been so different."

[Amanda, mother of Paul]

Parents frequently talked about professionals suggesting they have therapy themselves or attend parenting courses. Whilst professionals may not have intentionally been blaming parents when making such suggestions, parents felt that others were negatively judging them. For example,

“So many complaints and judgemental comments ... professionals suggesting I attend parenting groups ... I went on several ... family therapy ... we tried it ... counselling for myself ... if only I had the time ... be more consistent ... set clear boundaries ... be firmer ... I tried, I tried, I really tried.”

[Diane, mother of Andrew]

Another way in which parents perceived themselves to be judged by others was as being accused of being ‘overprotective’. For example,

“I’ve been told I’m overprotective ... maybe I am but there is nobody else out there willing to help him to take risks.”

[Amanda, mother of Paul]

There seemed to be no easy solution for parents, they were concerned that their son or daughter was overly dependent on them but worried that they could not cope without them. Parents were critical of professionals’ inconsistent approach to them, they felt that professionals saw them as overprotective but still relied on parents to support their son or daughter in the absence of other help. For example,

“He may be 25 in years but he’s still a young teenager in the way he thinks and acts ... people don’t understand this and somehow I have to protect him as you would be expected to protect a child ... but he’s an adult and so I’m told not to be so overprotective ... but who else is going to look after him?”

[David, father of Luke]

From the parents’ perspectives they had well-founded reasons to be ‘protective’ of their adult sons and daughters; they had had a lifetime of experience of what their

son or daughter could and could not do. And, as has already been pointed out, there was very little if any perceived support by professionals to help their sons and daughters move from a place of dependence on them as parents to living more independent or meaningful lives. In addition, if anything went wrong, they, not the professionals, were the ones left to 'pick up the pieces'.

6.6 On costs and benefits to parents

In this section the psychosocial costs and benefits on being a parent to an adult son or daughter with Asperger's syndrome is considered. Consequences for parents' health include the emotional cost of feelings of guilt, self-blame, sadness and worry, as well as the physical costs to them with exhaustion and tiredness being frequently talked about. Social costs include isolation, lack of social support, and the letting go of own needs, desires and ambitions.

6.6.1 Guilt and self-blame

For parents the emotional cost of caring for an adult son or daughter with Asperger's syndrome appeared high. The most commonly reported emotion amongst parents was that of guilt and self-blame. For example,

"I just kept thinking it must be me ... that if only I could be a better parent then he would surely be alright ... it must be me."

[Jenny, mother of Jack]

"I blame myself too ... was it something that happened when I was pregnant? Something I ate? I shouldn't have had that alcoholic drink when I was pregnant? Or maybe it was the way I was with him when he was born ... I was quite depressed."

[Judy, mother of Daniel]

Parents also felt guilt when doing things or when having a good time without their son or daughter. For example,

“You feel guilty going out and having a good time and you know your son is at home on his own.”

[Carol, mother of Carl]

6.6.2 Sadness and worry

Some parents talked about the sadness and worry involved in living with a son or daughter who could at times be very anxious, depressed, and for some suicidal. For example,

“I’m so worried that he will get worse and he will try to take his own life ... he’s so very fragile. This ... all this ... has had huge implications for our family ... huge ... I’m going to cry I’m sorry ... I have to be so brave for him ... it’s far worse for him ... he’s had 23 years of torture ... that’s what life is for him.”

[Sandra, mother of Matthew]

Thus worry was a major feature of parents’ lives. They worried on a daily basis about whether their son or daughter would get through each day without encountering too many socially difficult situations. They worried about their son or daughter’s mental health and about their longer-term futures. This inevitably had a cost to parents physically, notably many reported feelings of exhaustion and tiredness. For example,

“I can’t remember not being tired since I had Tim ... everything with Tim has been hard work and still is ... he drains me physically, emotionally and mentally ... I’m so tired ... it’s never ending.”

[Fran, mother of Tim]

Overall, the emotional costs to parents appeared to vary considerably, for some it seemed to be very high while others appeared more able to cope and more willing

to accept their circumstances. Some parents seemed angry and resentful about their son or daughter's circumstances. The following excerpt a mother describes herself as completely broken down by it all,

"He saps me dry ... actually I feel completely broken down by it all and you just wonder how much more you can take."

[Jill, mother of Martin]

In another excerpt, however, a mother describes her mixture of sadness and happiness,

"It is sad because I suppose it is not natural ... if you think of it in a biological way that the whole point of having children is for them to grow up and be independent and have their own family [...] so it's against nature in that way [...] I think although he's happy at home ... we all get on very well there are no tensions ... we are all very happy."

[Carol, mother of Carl]

Thus the emotional cost to parents did vary, some finding their circumstances more difficult to live with than others. It was not possible within this study to explore the reasons behind this. The next section looks at the different social costs to parents.

6.6.3 Isolation and lack of social support

Isolation and lack of social support networks were commonly talked about as being problematic for parents. Not only did parents feel guilty when not including their son or daughter in their own social activities but parents also highlighted how having a child who was a 'loner' affected their own opportunities to meet other parents and form supportive friendships. Several parents found themselves becoming more and more socially isolated in parallel with their child. For example,

“He was never invited back to other children’s houses or to parties, nobody ever called for him [...] I’m a very sociable person so I found that difficult because it isolated me too ... I didn’t get to know any of the other parents.”

[Amanda, mother of Paul]

“In the past he would sometimes upset the neighbours and only stoic friends put up with us ... we became more and more isolated ... it’s still isolating ... I still don’t like leaving him ... people forget parents become isolated too.”

[Carol, mother of Carl]

Thus parents found themselves as a whole family ostracised from normal social circles forgoing their own personal needs and desires, as well as having fewer informal social networks around them to support them in their daily lives. For some parents pursuing new personal and intimate relationships was a problem because their son or daughter found it difficult to adjust to another person in their parent’s life. For example,

“It’s not much of a life as it is but I want to spend some time with Jim [new Partner] ... the last time Jim came over here and stayed the night Matthew came into my bedroom about 2 in the morning saying “I can’t get to sleep ... I can’t get to sleep” and had terrible palpitations ...of course Jim felt terrible...because Matthew is suicidal and he felt he couldn’t risk making Matthew any worse than he was ... now he won’t come over any more ... so it’s very difficult.”

[Sandra, mother of Matthew]

6.6.4 Unfulfilled aspirations and ambitions

Another social consequence for parents was the forgoing of their own personal hopes, dreams, and aspirations. Some parents had unfulfilled ambitions that had long been cherished for when their children were no longer so dependent on them.

For example,

“We have always said that when the kids left home we would sell up and buy a boat and go off on the boat ... we can’t because Richard is still here and we can’t just abandon him.”

[Jane, mother of Richard]

Whilst most parents accepted being unable to ‘move on’ themselves and fulfil their own social ambitions, a few sounded desperate and even resentful about the situation they found themselves in. For example,

“I can’t ... I wouldn’t go and leave Martin but I resent the fact that I can’t do things ... I think well I’m 45 now and I had my children young in order that I could ... I did it consciously so that when I was older I could do things that perhaps I wanted to do and I envisaged myself travelling at this age and I can’t because I always have to think about Martin at home and I don’t feel I should have to be doing that now.”

[Jill, mother of Martin]

Thus the social cost to parents included dimensions of both the lack of opportunity to form and maintain social networks, being ostracised by others because of their son or daughter’s behaviour, and having to give up their own personal desires, hopes and ambitions for their own lives.

6.7 Summary

The phenomenon of *not quite fitting in* for parents has been presented in this chapter. Parents in this study appeared to have taken on ‘covert’ caring roles and responsibilities because they were carrying out non-obvious forms of support for their adult sons and daughters without their son or daughter’s knowledge, and with little or no recognition or support from formal or informal sources of help. These parents perceived that they *did not quite fit into* everyday norms of parenting adult children, nor did they fit into their notions of what it means to be ‘parent carers’ of disabled adult children. Conflicting dimensions of *not quite fitting in* included ‘letting go’ versus ‘holding on’ and ‘normalising’ versus ‘differentiation’. These dimensions amongst others have been discussed in relation to being a parent to a young adult with Asperger’s syndrome, the ‘covert’ nature of their caring activities,

the perceived responses of others, and finally the health and social costs to parents was considered. It has been suggested that parents ‘acquire’ the experience of *not quite fitting in* as a result of being a parent to a son or daughter with Asperger’s syndrome. This is in stark contrast to the young adults’ experience of *not quite fitting in* being a result of their own innate attributes.

Chapter seven

Theoretical literatures

7.1 Introduction

In this chapter, the main theoretical literatures that emerged as relevant to the concept of *not quite fitting in* will be considered prior to the discussion of findings. Symbolic interactionism is the main body of literature that will be outlined since this is the basic theoretical perspective used to analyse the findings. Supporting literatures that attempt to make sense of the experience of ‘human difference’ from the perspectives of mental health and disability studies will also be briefly discussed. This chapter is situated between the findings chapters and the discussion chapter because these literatures were sought out as having potential relevance to the phenomenon *not quite fitting in*. Thus, this chapter ‘sets the scene’ for the discussion of the findings from a symbolic interactionist perspective.

The first section of this chapter will set out the theoretical origins and premises of symbolic interactionism, the theoretical framework that underpinned the analysis of the study findings. The second section of this chapter explores the overlapping themes of ‘self’, difference and labelling. There are many varied sources of knowledge to draw upon in looking at this subject, the origins of which are largely rooted in seminal sociological studies of ‘deviance’ derived from a symbolic interactionist perspective (Goffman 1959, 1963; Becker 1963; Scheff 1966, 1996). The influence of these sociological theories to mental health and disability studies will be explored. The main themes highlighted will include the everyday language we use and the ‘labels’ applied to people who in some way ‘differ’ from others, whether it be cognitively, psychologically or physically. Finally, fictional accounts of human difference, both classic and modern, will be drawn upon to illustrate that *not fitting in* has long been a subject of human interest, and that there are alternative

ways of portraying and understanding the effects on ‘self and society’ of being ‘different’ (Steinbeck 1937; Camus 1942; Haddon 2003). As diverse as these spheres might seem, they share core values that seek to challenge the basic assumptions and fundamental beliefs that many of us hold about how people should look, think and behave. Thus the thread of the chapter will be about how people variously judged as being ‘different’ are theoretically, clinically and fictionally perceived, talked about and ultimately labelled.

7.2 Symbolic interactionism

This section outlines the theoretical perspective of symbolic interactionism and why this theoretical framework became central to guiding the analysis and interpretation of the current study findings. This will be important to bear in mind when reading the discussion of findings in chapter eight.

7.2.1 Relevance of symbolic interactionism

As discussed in chapter three, symbolic interactionism is an influential perspective that underpins the grounded theory methodological approach (Glaser and Strauss 1967). Whilst Glaser (1998:44) states that the grounded theory strategy is “*just a method*” and warns against ‘forcing the data’ into preconceived theoretical schemes, Blumer’s (1969) description of the methodological principles of symbolic interactionism has clear parallels with the grounded theory method and goals. It was in exploring the roots of grounded theory that the relevance of symbolic interactionism to the study emerged. Nevertheless, it was not the relationship between grounded theory and symbolic interactionism that led to the analysis of findings from this perspective per se. Glaser (1998) is critical of the assumption of

some researchers that grounded theory and symbolic interactionism are necessarily synonymous. He argues that any other theory or body of literature must 'earn their way' into the study through 'relevance', 'fit' and the ability to contribute to the emerging theory (Glaser 1998). In the study, *not quite fitting in*, emerged as the central phenomenon to account for participants' perceptions of difference, or in not being quite the same as others. This led to the exploration of literature of human difference, largely from mental health and disability studies. This literature frequently referred to classical sociological concepts of deviance, for example, Goffman's work on the presentation of self in everyday life (Goffman 1959), stigma (Goffman 1963), deviant career (Goffman 1968), Becker's (1963) theory of labelling, and Scheff's (1966) application of this work to labelling people as mentally ill. Furthermore, these authors themselves appeared to have been heavily influenced by the school of symbolic interactionism (Mead 1934; Cooley 1942; Blumer 1962, 1969). Thus I was redirected to the literature on symbolic interactionism and was struck again by the relevance of symbolic interactionism in trying to understand the experiences of young adults with Asperger's syndrome and how their fundamental difficulties in socialisation and social interaction affected their perception of 'self' and others, and, in turn, how this affects the ongoing experiences of their parents, and their own sense of self.

Symbolic interactionism, therefore, appeared to be a useful approach in exploring how people interact and how they make sense of their experiences throughout life, and how interaction with others helps give shape to the meaning in people's lives. Porter (1998:85) explains the main focus of symbolic interactionism,

“Symbolic interactionism, as its name suggests, concentrates on the dynamics of interaction between individuals [...]. Its aim is to explain social actions and interactions in terms of the meanings that those actions have for social actors.”

The attention to the dynamics of interaction between individuals became especially relevant to the findings of the study, which is principally about young adults experiencing difficulties in their everyday interactions and who display social actions that lack a sense of shared ‘symbolic’ meanings between themselves and others. Thus it seemed appropriate to discover more about the concepts underpinning the development of symbolic interactionism itself.

7.2.2 Origins and premises of symbolic interactionism

In understanding the symbolic interactionist perspective, its origins through the work of George Herbert Mead (1934) and his pupil, Herbert Blumer, are relevant. Whilst Blumer (1962) coined the term ‘symbolic interactionism’, he credits Mead as his chief influence in developing the perspective and research method (Blumer 1969). Blumer (1969) also acknowledges the contributions of a wide range of other North American scholars of the time, whom influenced Mead, including Dewey (1859-1952), Thomas (1863-1947), and Cooley (1864-1929). Elliot (2001) describes how Mead (1934) drew heavily from these various authors to develop a powerful account of the ‘emergence of self’, that will be described in the next section. The first major assumption underlying symbolic interactionism rests on the belief that individuals act on the meaning that events have to them, and secondly, that the meaning of these events comes from interaction with others. Thirdly, that this interaction with others is based on the communication using ‘symbols’, which consist of words, body language and other human attributes. Blumer (1962:180) refers to symbolic interactionism as,

“The peculiar and distinctive character of interaction as it takes place between human beings. The peculiarity consists in the fact that human beings interpret or ‘define’ each other’s actions instead of merely reacting to each other’s actions. Their ‘response’ is not made directly to the actions of one another but instead is based on the meaning which they attach to such actions. Thus human interaction is mediated by the use of symbols, by interpretation, or by ascertaining the meaning of one another’s actions”.

According to Blumer (1962, 1969), human action is an ongoing process involving participants conducting their lines of behaviour, on the basis of their interpretation of their situation. If the meanings, definitions and interpretations that sustain established patterns of social life are undermined, the pattern of social life will collapse. A further assumption relevant to the discussion of findings is that humans use ‘sympathy’, or empathy, in an attempt to understand the world of others (Cooley 1942). Thus we try to put ourselves into the other person’s situation, into his or her definition of the situation and into the interpretations the other person is making, that is, into the meaning an incident or an object has for that person. This in turn helps facilitate the ability to imagine the lives of others who are unfamiliar to us, and without this ability it would be impossible to interpret and understand the lives of others. This perspective appears to bear relevance to understanding why people with Asperger’s syndrome, which is fundamentally a disability of social interaction, behave in certain ways, because according to the premises of symbolic interactionism if a participant cannot readily interpret others’ actions and symbolic meanings, their behaviour is likely to be ‘out of sync’ with society, which in turn affects how others interpret the behaviour and thus how they respond. These ideas link to George Herbert Mead’s notions of the ‘self and society’, whereby, emphasised Mead (1934), each of us, as individuals *“fashion a sense of our own selfhood through engagement with other selves”* (Elliot 2001:25). Mead’s (1934) influential theory of the ‘self’ will now be elaborated on.

7.2.3 Mead's concept of 'self'

The first thing to address here is what the 'self' means. Elliot (2001) highlights how 'selfhood' is a complex term and that "*different social theories adopt alternative orientations to mapping the complexities of personal experience*" (p9). To consider the vast number of theories of self is beyond the scope of this thesis. However, as mentioned, the concept of 'self' as discussed by Mead (1934) is being highlighted for its relevance to making theoretical links with the findings and ultimately helping to make some sense of participants' central concern, the phenomenon of *not quite fitting in*.

In his posthumously published collection of lecture notes *Mind, Self and Society* (Mead 1934), Mead develops a notion of the 'self' as the 'agency through which individuals experience themselves in relation to others'. According to Mead (1934), having a 'self' involves the capacity for 'reflexivity', that is, to think back on our thoughts and activities and to see ourselves as others see us. Furthermore he suggests that this capacity is developed through the 'childhood process of socialisation'. Mead places considerable emphasis on the play of infants and young children in the emergence of a sense of 'self', for it is through play that the small child learns about the social world and interacting with it. Initially, notes Mead (1934), children play at being other individuals, such as their mother and father, however, once they begin to play games that involve others, they develop an awareness of their relationship with other players. In this way children begin to gain an understanding of the collective viewpoint of others around them; in Mead's (1934) words they take on the attitude of the 'generalised other'. Furthermore, Mead (1934) thought that in the play of children, one can 'glimpse the rudiments of differentiated social order', how different roles interact and reciprocate

responsibilities and duties. This pattern becomes integrated as part of the 'self'. Cooley (1942) further argues that the connection between society and self are inseparable, saying the "*self and society are twin-born*" (p5). According to this view, the 'self' only develops through our incorporation of the views of others; in Cooley's words, it is a 'looking-glass' self. Mead (1934) further makes a crucial distinction between the 'I' and the 'me' in conceptualising the self. The 'me' is the socialised self that is made up of the internalised attitudes of others, and the 'I' is the unsocialised self, an assortment of personal desires, needs and dispositions. The achievement of self-awareness, says Mead (1934), arises when the self is able to distinguish the 'me' from the 'I'. However, Mead (1934) also makes an important and seemingly neglected point about the role of the unsocialised 'I' self in relation to society, for,

"It is in such reactions of the individual that the 'I' over and against the situation which the 'I' finds itself, that important social changes take place. We frequently speak of them as expressions of the individual genius of certain persons ... persons who will have a formative effect upon the society to which they belong" (p217).

Mead appears to be saying that society is changed, and develops, through the expressions of the 'individual' whose thoughts and actions are not bound with conforming to the situations and society in which they find themselves. Thus, this suggests a potential value to society of some people being 'self' immersed, free from the influence of the majority. This will be further explored in relation to the findings in chapter eight.

7.3 Sociological concepts of human difference

This section briefly considers the seminal works of sociologists Erving Goffman (1959, 1963) and Howard Becker (1963) and their contribution to our understanding

of human difference and the association between social interaction, deviance, labelling, discrimination and the reduction of life chances.

The work of Goffman (1959, 1963) famously introduces the concept of 'social identity' to describe personal qualities that remain constant across situations. In his celebrated work, *The Presentation of Self in Everyday Life*, Goffman (1959) provides an analogy of the structures of social encounters from the perspective of actors in a dramatic performance, in which he argues that we all hold well-practised behavioural routines or scripts, which ensure some continuity in the way we behave across different situations and before different audiences. Goffman (1959) portrays how people use 'fixed props' such as houses, clothes and job situations in 'front stage' performances to present the social identity, but he also describes a 'backstage' region where people both prepare their images and relax from them. He also painfully demonstrates what can happen when a performance falls flat. Furthermore, Goffman (1963) elaborated on his ideas of social identity, by signifying that these social identities can be consolidated or spoiled by the reactions of others towards us whereby negative judgements may result in damaged identities. Goffman calls this 'spoiling of identities' the process of 'stigmatisation'. He defines 'stigma' as "*a special kind of relationship between attribute and stereotype [...] because there are important attributes that almost everywhere in our society are discrediting*" (Goffman 1963:14). Goffman (1963) also distinguishes between the 'discredited' and the 'discreditable' depending on whether the individual's differences are already known about or are instantly evident, or that the differences are neither known about by those present or immediately perceivable. Furthermore, Goffman (1963) suggests three grossly different types of stigma: physical

deformities, blemishes of character, and the tribal stigma of race, nation and religion,

“In all these instances of stigma an individual who might have been received easily in ordinary social intercourse possesses a trait that can obtrude itself upon attention and turn those of us he meets away from him, breaking the claim that his other attributes have on us [...] by definition we believe the person with a stigma is not quite human and we exercise varieties of discrimination, through which we effectively, if unthinkingly, reduce his life chances” (p15).

Thus Goffman (1963) believed that there are a variety of ways in which people are perceived as ‘different’ from others, and also a variety of ways in which people are discriminated against. Notably, the process of discrimination takes place through social contact and the ‘obviousness’ of the offending attribute/s. This ultimately has an adverse effect on the life chances for the person judged as different. Working at the same time as Goffman, Howard Becker (1963) developed similar concepts on the nature of human deviance and the process of labelling people as such. This work was also rooted in the ‘Chicago’ traditions of symbolic interactionism. His work entitled *Outsiders* (Becker 1963) defines ‘deviance’ as the identified failure to obey group rules that is followed by a process of labelling. The failure to obey group rules does not automatically constitute the person being deviant; in order to be perceived as ‘deviant’ a person must first have ‘successfully’ had the deviant label applied. Becker (1963) describes the subsequent process of how ‘successfully labelled deviants’ become seen and treated as ‘outsiders’. Within this viewpoint he also identifies that ‘just how far outside one becomes’ varies from case to case dependent on the degree of visibility and significance that others attach to the deviant behaviour.

These sociological concepts of difference or 'deviance' continue to pervade contemporary sociology. For example, Aggleton (1987) provides various examples of obvious deviant behaviour in today's society: rape, child abuse, terrorism, football hooliganism and juvenile delinquency, as well as less obvious forms such as alcohol dependence, childlessness and even stuttering. Drawing on the works of Goffman (1959, 1963) and Becker (1963), Aggleton (1987) distinguishes between actions and behaviours that break the law and others which simply go against expectations or standardised ways of acting; the infringement of expectations of norms he calls deviance and the breaking of laws crime. However, he also points out that these categories are not always mutually exclusive with some acts both simultaneously breaking social norms and criminal laws and other acts infringing laws but still consistent with community norms. Aggleton (1987) goes on to address the different norms between cultures, where actions frowned upon in one culture can be positively accepted in others. Thus, says Aggleton (1987:6), we could define deviance as "*behaviours which run contrary to norms existing in the society, group or community in which the behaviour occurs*". However, problems with this approach arise when norms governing behaviour vary from situation to situation within a culture as well as between cultures, which led Aggleton (1987) to introduce the sociological term 'subcultures', such as family groups, work groups, leisure groups each with their own norms. This will be relevant in chapter eight when discussing participants who did *not quite fit in* to their peer groups and for some, even their families.

7.4 Some lessons from mental health and disability studies

In this section, some lessons from the experience of human difference and the consequences of being labelled are drawn from the fields of mental health and disability studies. For example, Scheff (1996) and Rosenhan (1996) both draw upon the symbolic interactionist labelling theories in their theses of the labelling of different behaviour as 'mental illness'. In addition, the field of disability studies has much to offer in terms of a rich discourse about the perception, language and effects of human differences.

7.4.1 Labelling behaviour

In considering the labelling of different behaviour as mental illness, Scheff (1996) argues that of all the major diagnostic categories the concept of 'schizophrenia' is the 'vague and least clearly defined', the symptoms of which can be redefined as offences against implicit social understandings. I suggest that this could equally apply to the diagnosis of Asperger's syndrome that is also made on the basis of social interaction and behaviour and continues to have problems with definition (Rutter 2005) and the confines of its boundaries are unknown (Fombonne 1999, 2005). In discussing the process of labelling behaviour as mental illness, Scheff (1996:69) points out,

"In social interaction there is a public order that is continually reaffirmed. Each time a member conforms to the stated or unstated cultural expectations of that society, as when he gazes in the eyes of the person with whom he is conversing, he helps maintain the social status quo. Any deviation from these expectations, however small and regardless of its motivation, may be a threat to the status quo".

Furthermore, according to Scheff, any threats to this status quo lead the conforming members of society to look to 'extra social sources of legitimacy' to maintain the

status quo. Within differing societies throughout history, says Scheff (1996), this task has fallen to either religious or supernatural forces or medical healers, and in modern societies medical science has increasingly become the important source of legitimacy by labelling non-conformity as mental illness. Thus, says Scheff (1996) labelling people who threaten the social status quo, as 'mentally illness' has become a vehicle for control through medication and/or enforced institutional confinement. Thus, along similar lines to Scheff (1996), also drawing on Goffman's (1968) concept of mental illness as a 'deviant career', Rosenhan (1996) describes a psychiatric label as having 'a life and influence of its own', so for example, once the impression has been formed that a person has schizophrenia, the expectation is that he will continue to be schizophrenic even in the absence of symptoms or bizarre acts. Thus the label itself influences how the person perceives him/herself and on how others perceive and treat him or her,

"Those who have dealings with them fail to accord them the respect and regard which the uncontaminated aspects of their social identity have led them to anticipate extending, and have led them to anticipate receiving; they echo this denial by finding that some of their own attributes warrant it" (Rosenhan 1996:8-9).

However, as Scheff (1996) also discusses, differences in social interaction, however small, will affect how a person is perceived and accepted by others. Thus in the absence of a medical diagnosis people who do not conform to norms of social interaction become subject to a number of negative 'everyday' labels, for example, mad, bad, or weird. As with people experiencing mental distress, people with disabilities have also long been subjected to various labels, for example cripple, cretin, fool and idiot (Ryan and Thomas 1980). Ryan and Thomas (1980) note that in a continuous search for more neutral terms, disability labels frequently replace each other. For example, what was once 'subnormal' became 'handicapped', which

in turn became either 'impairment' or 'disability'. Furthermore say Ryan and Thomas (1980), whereas in past times terms like 'cripple', 'cretin', 'fool' and 'idiot' were commonplace, such terms have become forms of abuse without thought to the original meaning. Writing on disability studies, Marks (1999) also illustrates how vocabulary is frequently used abusively,

"A person who is not aware of their surroundings and fails to notice something is blind, a person who fails to listen is deaf, while a person who fails to understand something may be taunted with the term retard" (p138).

Marks (1999) argues that such negative use of language feeds back into our images of disabled people, both generalising and exaggerating the effect impairments have upon people. Thus, says Marks (1999:138), *"disability language functions as a metaphor for 'something else'"*; but just what that 'something else' stands for varies considerably. Therefore, she argues, the language we use can play an important role in 'disabling' people by removing disability from 'mundane human experience and elevating it as radically other' (Marks 1999). Thus, in disability studies, a prevailing discourse surrounds the language we use and the way in which disabled people are perceived (Marks 1999). Even the terms 'disability', 'impairment' and 'handicap' are controversial and not internationally universal. For example, explains Marks (1999), in some languages, translations of the term 'impairment' have profoundly negative meanings, whilst the term 'handicap' is often rejected because of the nuance of being 'cap-in-hand', or begging. In the UK the term 'impairment' is currently accepted to refer to bodily or mental aspects of the disabled person, and 'disability' is often used to describe 'social barriers' (Marks 1999; Priestly 1999), described by Oliver (1998:1447) as the *"social restrictions imposed by an unthinking society"*. This 'social model of disability', or 'oppression theory' regards disability as a social and political issue rather than a medical one,

and thus social and political solutions are sought rather than medical cures, to challenge disabling discrimination. The aim is move away from focusing on the 'impairments' that distinguish people from one another, and to increase autonomy, choice and respect (Marks 1999). Thus instead of examining particular problems that arise from the negative state of 'not seeing' or 'not being able to walk', the social model looks at the ways in which the environment is designed for the removal of disabling socially constructed barriers (Oliver 1993). This view of disability opposes popular beliefs about a disability being what someone has when their body or mind doesn't work properly. For example, a person who is paralysed, blind or deaf is disabled. According to the social model of disability the medical view of disability assumes that disability is a 'tragic aberration' (Oliver 1991, 1993, 1998) that afflicts a minority of people and that it is this 'pervasive view that shapes much of the medical, social and educational treatments of disabled people'. Although the model of disability as a socially constructed phenomenon is a widely accepted premise for those involved in disability studies, it is not without its critics. Abberley (1993) argues that paradoxically the move beyond the individual to the social has resulted in a more pessimistic prognosis for disabled people, *"If the problem of attitude is not primarily located in the individual, but in the society, then no amount of individual effort at 'adjustment' to impairment can solve it"* (p109). French (1993), a lecturer and qualified physiotherapist with a visual impairment, agrees with the basic tenets of the socially construed model of disability, but also cautions against solely focusing upon adjusting the social and physical environment to improve the lives of disabled people. French (1993:17) says,

"I believe that some of the most profound problems experienced by people with certain impairments are difficult, if not impossible, to solve by social manipulation. Viewing a mobility problem as caused by the presence of steps rather than by the inability to walk, or regarding the inability to access information as due to the lack of sign language rather than to a hearing impairment, is easy to comprehend. Examples such as these are frequently put forward when the social model of disability is being explained. However, various profound social problems that I encounter as a visually impaired person, which impinge upon my life far more than indecipherable notices or the lack of bleeper crossings, are more difficult to regard as entirely socially produced or amenable to social action".

Thus, whilst French (1993) fundamentally agrees with the need for society to remove many socially constructed disabling barriers, she recognises the complexity of this as the 'profound social problems' she encounters, due to her visual impairment, cannot all be addressed through social action.

In summary, discourses of 'difference' in the fields of mental health and disability highlight some of the problems of language, social interaction and society's responses to people who are in some way 'different', whether mentally or physically. The role of the health service and medical diagnosis has been questioned both in labelling mental illness, and in the view of physical disability as a 'tragic aberration' (Oliver 1991). Writers prominent in the field of physical disability, such as Oliver (1991, 1992, 1993, 1998), argue for the removal of social barriers. However, whilst ramps can be put in place, doorways widened and lifts installed, the social barriers found in human attitudes and reactions to difference (that threaten the status quo of a community, culture or society) are far more complex to contend with. Finally, this chapter briefly considers alternative 'ways of knowing' and understanding people who do not quite fit in, by illustrating some fictional portrayals of human difference.

7.5 Fictional portrayals of human difference

“Fiction can sometimes be truer than fact” (Darbyshire 2002)

Darbyshire (2002) suggests that classical literature has a place within qualitative research, as this source of ‘knowing’ can have much to say to its readers about human nature. The classic books *Of Mice and Men* by John Steinbeck (1937), and *The Outsider* by Albert Camus (1942) are exemplary works of fiction that portray human difference and society. In addition, contemporary works, such as, *The Curious Incident of the Dog in the Night-Time* by Mark Haddon, have attempted to deal with the issue of *not quite fitting in*. The first two books portray men living lives on the edge of societal norms. In each the main characters commit crimes of murder and are subsequently judged by others as being evil men, who consequently, must be most severely punished, in the most ultimate of ways, by execution. In both cases the accused are guilty of killing, and although judged as murderers, neither of them killed with premeditated or murderous intent. They were both far from being evil, but rather seemed strangely innocent. Similarly, Haddon’s (2003) novel, documents human naivety and poor social understanding, and is unique as he attempts to describe the experiences from the viewpoint of the central character, a teenage boy with Asperger’s syndrome.

Set in 1930’s depressed America, *Of Mice and Men* Steinbeck (1937) portrays the guilty but innocent (of intent) ‘Lennie’ as possessing physical strength beyond his control. As the story unfolds it is shown how Lennie inadvertently kills mice, and his adored puppy, by crushing them to death when actually meaning to protect them. Eventually he inadvertently kills another man’s wife. Lennie’s physical size and strength proved powerless against the social and cultural laws of the times, he is utterly misunderstood, by all but his friend George, and both he and George are

defenceless against a society which only sees a 'half-wit' murderer who deserved to die for killing a woman.

In the case of the character 'Meursault' in *The Outsider* (Camus 1942), Meursault was also condemned to death by society, not for his action but by his reaction to the event of killing a man in an unseen act of self-defence. Meursault showed no remorse for his action because he believed himself to be innocent of murdering a man because it was (in his mind) self defence, which in law at the time was permissible, however, it seemed inconceivable to the onlookers that he could not regret what had happened. There were other factors regarding his character and previously odd reactions that led to his downfall, such as, his failure to follow the normal strict mourning rituals when his mother died, and when asked to say he regretted his crime he replied that he felt 'more annoyance than regret'. Since there were no witnesses to the killing, it was aspects of his character that were ultimately tried in court and that led to his being found guilty. The jury and people around him just could not understand a belief system that differed from their own. They could not accept someone who was wholly truthful and non-hypocritical, because Meursault did not appear to know how to act and speak as the crowd expected him to do. Contrary to what the crowd thought, he did not deliberately violate social expectations; Meursault 'literally' could only speak and act truthfully, and so he had no choice. He had no concept of speaking or acting in ways to help others judge him favourably; he could only speak the truth, as he perceived it. Paradoxically, if the crowd had understood this they would have recognised his innocence rather than perceiving his odd responses as threatening and dangerous. Equally, had he been able to lie and act as others expected of him, he would also almost certainly have been acquitted of the crime.

The question is why these books, written so long ago, have become popular classics of today enduring the changes of time and culture? Both are novels that deal with the theme of 'outsiders' (individuals who do not fit into the mainstream of society), and portray human nature throughout the ages. The reader of yesteryear and today can alike, ponder the similarities found in their own communities; how we so often seem to misunderstand and make no attempt to try to understand others who appear in some way or another 'different' from ourselves. Or, how we tolerate, or not, differences that threaten the social and cultural norms that make up our existence, and according to Mead (1934), Goffman (1959, 1963), and Scheff (1966, 1996), form the basis of our 'self' identities.

Finally, Haddon's (2003) contemporary work of fiction is of interest as it convincingly portrays the thoughts and behaviour of a 15-year-old, Christopher, with Asperger's syndrome, thus helping to raise popular awareness of this particular form of 'difference' or *not quite fitting in*. Described as stretching 'the boundaries of fiction into the realm of psychology and psychiatry' (Merikangas 2003), Christopher is not being held up as typical of Asperger's syndrome, but the book does seem to convey a sense of what it must be like to have Asperger's syndrome, as well as some of the challenges for parents. The book begins with the sight of a dog that has been killed with a pitch-fork. Christopher, who attends a school for pupils with special needs because of his poor social understanding and 'behavioural problems', sets out to solve the crime requiring him to interview witnesses, deal with accusations that he committed the crime, and negotiate his father's anger and his mother's disappearance. In his small neighbourhood, a boy digging up clues is a powerful literary mechanism for not only illustrating the mind and actions of a

person with Asperger's syndrome, but also for exposing social relationships (Baron-Cohen 2004). Interestingly, many reviewers, 'expert' in the field of 'autism' studies and clinical practice, extol Haddon's book for providing insight into how the world is perceived by a person with Asperger's syndrome. For example, on the book cover Sacks (2003) writes, "*Mark Haddon shows great insight into the autistic mind*". However, Talley (2005:244) is suspicious of "*narratives touted as real accounts of disability when they are not produced by disabled people*". Talley appears to be writing from a social model of disability perspective, rather than as a person with Asperger's syndrome herself. This view contrasts to Willey (1999), herself a person with Asperger's syndrome, who writes,

"It is almost impossible to believe author Mark Haddon does not have an autistic spectrum disorder, so sweetly accurate is his insight into what life with autism is like for many. Readers will step into the soul of autism when they read 'The curious incident of the dog in the night'. And they will like that soul." (p687).

Thus, whilst Talley raises an important point that we must be cautious of reading popular representations of disability and to consider the question of how disability accounts are produced and read, we can also draw on these writings to stimulate thought and direct further study into the experience of others.

7.5 Summary

This chapter has sought to set out the theoretical literatures drawn upon in further analysis of the findings, which provide the backdrop to the following chapter, discussion of findings.

Chapter eight

Discussion of findings

8.1 Introduction

This chapter focuses on a theorising discussion of the findings as reported in chapters five and six. The purpose of the discussion is to integrate the emergent phenomenon *not quite fitting in* into the wider body of knowledge by comparisons with appropriate literatures; including theoretical, empirical and biographical. Thus, as discussed in chapter seven, by searching the literature for explanations of human difference, I kept returning to a literature of 'deviance' rooted in the traditions of social psychology (Goffman 1959, 1963; Becker 1963; Scheff 1966, 1996). These influential writers had themselves been influenced by the symbolic interactionist perspective (Mead 1934; Blumer 1962, 1969). On examination of the theoretical premise of symbolic interactionism, some striking links between symbolic interactionism and the study findings became evident for the 'self' in relation to others. For example, questions emerged regarding the absence of 'symbols' in symbolic interaction, which raised questions about the consequences of what I describe as 'symbolic miscommunication'. Whilst it is interesting to note the influence of the symbolic interactionist school of thought on grounded theory methodology through the contributions of Anslem Strauss, symbolic interactionism was not something I considered important at the outset of the study. As Glaser (1998) advocates, other theory is only relevant if it can 'earn its way' into the analysis. Thus, the core category of *not quite fitting in* emerged from the data, and was then further analysed from the perspective of symbolic interactionism. In doing this a symbolic interactionist perspective emerged that offered further explanations about the nature and consequences of *not quite fitting in* for young adults and parents 'living with Asperger's syndrome'.

By way of reminder this chapter will begin with an outline of the core category *not quite fitting in* for young adult *and* parent participants. The chapter will then endeavour to frame the findings within the concepts of symbolic interactionism resulting in a series of hypotheses regarding the development of ‘self’ for young adults with Asperger’s syndrome and their parents.

8.2 The core category - *not quite fitting in*

In this section the main findings in relation to the experience of *not quite fitting in* from the perspectives of young adult and parent participants are revisited and the multidimensional nature of *not quite fitting in* and the different nature of this phenomenon for young adults and parents are expanded upon. The core category *not quite fitting in* captures the apparent sense in the data that young adults and parents were not *quite* the same as others but not *quite* different either. For example,

“He just doesn’t seem to fit in ... he’s different from different ... not quite the same and not quite different”

[Fran, mother of Tim]

Thus young adult participants ‘looked normal’ and had normal intelligence, but behaved in ways that seemed ‘socially inept’, ‘socially awkward’, ‘inflexible’, and apparently ‘lacked empathy’. However, they themselves expressed ‘feeling different’ from others and had difficulty in identifying a sense of ‘self’ in relation to others. For example, many expressed feelings of not belonging anywhere, which included their own families.

Furthermore, *not quite fitting in* encompasses the experiences of parents who perceived their roles as neither fitting the role of a ‘normal’ parent nor fitting the

role of a 'parent carer' of an 'adult child' with a severe learning or physical disability. Most parents did not consider themselves to be 'carers', and young adults did not consider themselves to be 'cared for'. Nevertheless, when parents discussed their roles in young adults' lives, a considerable amount of 'caring' becomes apparent; psychological (psychological 'watching over', companionship, managing emotions) and practical (providing shelter, food, security, money). Much of this caring work of parents was carried out without the explicit knowledge of the young adults, and sometimes deliberately 'covertly'. Thus the unacknowledged caring role *did not quite fit* with parents', or young adults', notions of what constitutes caring.

Thus young adults, and the role of their parents, did not quite appear to square with everyday social constructs of 'normality' or 'difference'. This links with the work of Goffman (1963) who distinguishes between the visibility of a stigma and its 'known-about-ness'. This, he argues, affects the decoding capacity of others. In other words 'known-about-ness' affects other people's ability to interpret the nature of a person's disability. Interestingly in Goffman's view, a 'hidden stigma' is more likely to benefit the person affected by acting as a 'buffer' to the potential impact on the individual being 'discredited'. In direct contrast, some parent participants held an opposing view in that they wanted greater recognition for the social and psychological difficulties that their son or daughter encountered in society. This was because they perceived that others regarded young adults as neither 'different' nor the 'same'. In other words it would seem they were not '*different enough*' to warrant help from education, health or social and caring services but were '*different enough*' to be bullied and shunned by others with whom they came into contact. Thus parent participants seemed to be suggesting that it was the *not - 'quite' - ness* of

Asperger's syndrome that contributed to delays in diagnosis and the perceived lack of appropriate help. Parents consistently argued that had their son or and daughter been more obviously different to others, their needs would have been identified earlier in their lives. Furthermore, they argued that with earlier diagnosis, support systems, both professional and lay, could have been put in place promptly, as with other more obvious disabilities. For example, as one mother with an older son with an obvious learning disability argued,

"It was so different with Adam ... we knew before he was born [...] we were given counselling and support right away [...] everything for him was mapped out right from the beginning [...] but for Martin ... there's nothing"

[Jill, mother of Martin]

Thus, parent participants were arguing for more recognition and for their son or daughter to be helped to address their difficulties and to 'fit in' better with their social context. However, in contrast to parents, young adults did not appear to be arguing for help to 'fit in'. Rather they seemed preoccupied with the 'feeling' of 'being different', of 'alienation', and the apparent lack of a coherent 'sense of self'.

For example,

"I've always felt different [...] like I'm the wrong bit of the jigsaw... squeezed in ... not really fitting even though it looks kinda right ... but I don't really belong there ... I don't know who I am or where I'm meant to be"

[Andrew]

Some parents also identified a sense of 'alienation' between them and their son or daughter in that they were referring to the feeling that they were somehow separated from human ways of connecting to one another. For example,

"I find him so hard to reach, it's like we've lost touch ... and I don't, don't know how to find him"

[Diane, mother of Andrew]

In discussing human difference, Ryan and Thomas (1980:13) state, “*The assertion of difference between people [...] almost always implies some kind of social distance or distinction.*” Although not referring to people with more obvious learning difficulties, Ryan and Thomas (1980) capture the *not quite fitting in* predicament of young adults who appear socially distant from others and struggle with a sense of self in society. For example, in the current study few young adults discussed having any meaningfully close friendships throughout their lives, as well as their perception of not knowing themselves. The links closely with Mead (1934) and Goffman’s (1959) concepts of the relationship between self and society. Within the biographical literature, feelings of being socially distant and ‘alien’ from all of society abound. This is reflected particularly in the book titles of a number of published books; for example: *Nobody Nowhere* (Williams 1992), *An Anthropologist on Mars* (Sacks 1995), *A Real Person* (Gerland 1997), *Pretending to be Normal* (Willey 1999) *Asperger Syndrome, the Universe and Everything* (Hall 2001), *Freaks, Geeks and Asperger Syndrome* (Jackson 2003), and *Women from Another Planet* (Miller 2003). In reviewing the title of her book, Gerland (1997:15) comments, “*The name of [my] book is ‘A Real Person’ and that’s what I’ve always tried to be but never felt like. I’ve always wanted to become ‘normal’ or ‘ordinary’ or whatever I should call this*”. In this statement Gerland (1997) reveals her constant attempts to be ‘normal’. In the current study young adult participants repeatedly raised this as an issue. For example,

“I do wish I wasn’t afflicted by this ... I wish I could be more normal ... I don’t know this person ... me ... he’s a nobody”

[Thomas]

This excerpt reflects the link between the two concepts, 'normal' and 'self'. For some, the desire to find a sense of self appeared strong but achieving this seemed difficult. For example,

"I know that to achieve my real genuine person I have to go to extreme depths and that's where the suicide comes in"

[William]

However, the effort required to 'achieve' a sense of self seemed to some too difficult. Thus, young adults appeared to be having difficulties in identifying a sense of who they were in relation to other people. This can also be linked to Goffman's (1959) concept of the 'presentation of self in everyday life'. Goffman believed that our sense of 'self' and how we present this 'self' to others is tied to how others see us. However, a prerequisite for this sense of self is having some understanding of what others might be thinking and feeling. Extensive research in the area of 'theory of mind' suggests that people with Asperger's syndrome have considerable difficulties in understanding others' minds, known as 'mindblindness' (Baron-Cohen 1991, 1995; Happé 1994, 2003; Lawson, Baron-Cohen and Wheelwright 2004). This perspective suggests that young adults with Asperger's syndrome have an impaired ability to see themselves as others see them. This then makes it difficult for them to engage in what Goffman (1959) terms 'impression management', which involves acting in ways designed to favourably impress others. This hypothesis will next be explored further in relation to the development of 'self' from a symbolic interactionist perspective.

8.3 Asperger's syndrome, self and society

In this section the findings are interpreted according to the theoretical premises of symbolic interactionism. Mead's (1934) theory of 'self emergence' underpins symbolic interactionism and is discussed along with other symbolic interactionist theories including the meaning of communication through 'symbolic' interaction (Mead 1934; Blumer 1969) and labelling theories (Goffman 1959, 1963; Becker 1963; Rosenhan 1996). It is being argued that these seminal theories have resonance today and are thus drawn upon to help explain why young adult and parent participants experience the phenomenon of *not quite fitting in*, and how they were continually trying to resolve this in their everyday lives. The discussion will begin with an integration of the findings with Mead's (1934) concepts of the development of 'self' in relation to early childhood processes of socialisation.

8.3.1 Childhood socialisation and Asperger's syndrome

Based on Mead's (1934) theory of emergence, it is being hypothesised that the experience of *not quite fitting in* might originate from a lack of early social play. Many parent participants commented on their son or daughter's lack of willingness to engage in social activities in childhood and their unusual patterns of play. For example,

"He was always a loner. Philip's a loner. And he never liked going to children's parties... he wouldn't join in with children's games ... he didn't play like other children do".

[Mary, mother of Philip]

Parents frequently recalled how their son or daughter had been 'loners' as children, rarely engaging in social play activities. For example,

“When he was at playschool he didn’t mix very much [...]He couldn’t play any imaginative games [...] all Martin would do was to line them [toy soldiers] up in a long line, there was no sort of play there.”

[Jill, mother of Martin]

From Mead’s (1934) perspective, childhood play is critical in conceptualising the ‘emergence’ of a sense of self in relation to society. It is through play, notes Mead (1934) that the small child will learn about the social world and interacting with it. In role-playing children play at being a number of individuals, and begin to develop both an awareness of their relationship with others, and gain an understanding of the collective viewpoint of people around them. According to Mead (1934), it is through ‘taking on the role of the other’ in role-play that the child learns the skills of ‘reciprocity, co-operation, and begins to see oneself from the stance of the other’. One parent illustrates how as a child her son was unable to take the views of other children into account, and how this element of his character remains today,

“He would always want to dictate to other children ... he would tell them what to do and even what to say ... it had to be his way or none at all ... they soon got fed up with him. He can still be like that today ... if he doesn’t get his way on something ... even simple things like what TV channel to have on ... he will get angry or sulk terribly”

[Amanda, mother of Paul]

Whilst Mead (1934) did not seem to address the consequences of children not engaging in social role-play, the implications are clear. If such play is needed to understand the perspectives of others, to learn how to interact with others, and to develop a sense of self in relation to others, then its absence will impede the developmental processes of socialisation and emergence of self. Thus, from this viewpoint, young adult participants’ apparent lack of childhood social play is linked to later experiences of *not quite fitting in* as illustrated in the extract above.

There is a substantial body of knowledge surrounding the development of children with autism spectrum conditions demonstrating a marked lack of social interest from an early age, and the absence of pretend play (Kanner 1943; Asperger 1944; Wing and Gould 1979; Baron-Cohen 1987, 1995; Happé 1994; Charman et al 1997; Attwood 1998; Blanc et al 2005). Indeed, the lack of social interaction in children with Asperger's syndrome is detailed in some of the earliest accounts. For example, Asperger (1944:78) notes,

"The child sits preoccupied, perhaps apart in a corner, or even in the middle of a happy, noisy group of siblings or peers. He is like an alien, oblivious to the surrounding noise and movement, and inaccessible in his preoccupation. He is irritated only if someone breaks into his isolation".

Studies continue to report deficits in imaginative or 'symbolic' role-play in children with autism spectrum conditions (Baron-Cohen 1987, 1995; Blanc et al. 2005). However, it is important to note that not all forms of pretend play are absent in some children with Asperger's syndrome. Whilst studies of children with Kanner's autism have shown a marked absence of imaginative play (Wing and Gould 1979), reports of children with Asperger's syndrome have shown a propensity for 'unusually' imaginative games (Attwood 1998). Attwood (1998) observes how play in children with Asperger's syndrome can 'appear imaginative' but it may in fact be a perfect imitation of an original source, perhaps from a film or storybook. Furthermore, Attwood (1998) describes how, in contrast to 'ordinary' children's play involving favourite characters or people, the child with Asperger's syndrome often prefers becoming an 'object' rather than a person. He illustrates this with a quote from his clinical practice,

"One boy spent many minutes rocking from side to side. When asked what he was doing, he replied, 'I'm car wiper blades' – his current special interest. One boy pretended to be a teapot while a girl spent several weeks pretending to be a blocked toilet" (Attwood 1998:123).

Although these children seem to have the capacity for imaginative play, Attwood (1998) suggests that the content of this play will often involve objects rather than people, and importantly, they often do not involve other children in these 'solitary' games. Here the 'objective', 'solitary' pretend play of children with Asperger's syndrome does not fit with the social 'subjective' role-play involving others, regarded by Mead (1934) as necessary for learning the many skills of interaction. This activity, says Mead (1934), is critical in being able to take on the attitude of the 'generalised other' and for the development of 'self'. Thus, it is being argued that the experience of *not quite fitting in* begins with impaired early social play that disrupts the ability to engage in social interaction and blocks the development of 'self' in relation to others. In attempting to understand more about this, the discussion will now turn to the issue of social interaction and the 'symbolic' communication/miscommunication in young adults with Asperger's syndrome.

8.3.2 Miscommunication of gestures

This section presents the hypothesis that young adults' 'feelings' of *not fitting in* are related to a difficulty with the unspoken gestures and the 'taken-for-granted' aspects of communication. Such difficulty fundamentally disrupts relationships with others and thus interferes with any sense of belonging or connection with others. In suggesting this hypothesis, the findings are linked to a basic premise of 'symbolic' communication, that is, communication takes place through the use of 'symbols', and these 'symbols' represent 'objects in our own minds and in the minds of others' (Mead 1934; Blumer 1969).

Mead (1934:147) argues, *"We always assume that the symbol we use is the one which will call out in the other person the same response"*. In building on Mead's concepts, Blumer (1962:180) states, *"human interaction is mediated by the use of symbols"*. However, this assumes that both the communicator and recipient understand the 'symbols' being used. Mead (1934:147) further argues that 'symbols' have a *"universal character"* for the social groups in which they operate. For example, metaphors in everyday language act as 'symbols'. Thus the metaphor 'pull your socks up' is a 'symbol' that is generally understood by everyone to mean 'you need to do better'. However, it is being argued that to the person with Asperger's syndrome 'symbolic meanings' are likely to be difficult to interpret and therefore likely to be misunderstood thus 'literally' signifying the pulling up of socks. Although this is a simplistic example of a symbol that can be consciously learnt by the person with Asperger's syndrome, it is the context that is more difficult to distinguish. Thus knowing whether someone is asking you literally or metaphorically to 'pull your socks up' is the 'taken-for granted' aspect of communication that most children naturally grasp as they grow and develop. This is illustrated by a parent, who talked of her son's difficulty with the 'symbolic' concept of time, as well as her 'symbolic' gestures to hurry him along,

"He cannot understand when I tell him he's late for college because until it is past 10 o'clock he is not late ... even though I'll be jumping up and down and flapping around trying to hurry him up ... he takes no notice until he is actually late and then he panics"

[Judy, mother of Daniel]

Thus it would seem that young adults with Asperger's syndrome have difficulty in using or understanding shared symbols. Whilst Mead (1934) sees 'symbols' as a form of 'common currency' by which individuals can develop a sense of self and interact with others, it is being suggested that people with Asperger's syndrome do

not seem able to use this 'currency' in everyday life. Hence communication becomes limited to 'literal' meanings of verbal speech rather than the unseen and unshared 'symbols'. From Mead's (1934) perspective, they do not share in the everyday 'conversation in gestures', which refers to the non-verbal aspects of interaction that *"cannot be translated into articulate speech"* (Mead 1934:14). This includes both hidden and double meanings within speech as well as non-verbal gestures. To explain this, Blumer (1969) states that 'gestures' found in everyday interactions (including eye contact, facial expressions, glances, nodding or shaking of heads) are used to convey to the person who recognises them an idea of 'intention and plan of forthcoming action of the individual who presents them'. Blumer (1969) states that the person who responds,

"organises his response on the basis of what the symbols or gestures mean to him; the person who presents the gestures advances them as indications of what he is planning to do as well as of what he wants the respondent to understand. Thus, the gesture has meaning for both the person who makes it and for the person to whom it is directed" (p9).

In relation to young adult participants, the way in which they non-verbally interacted when being interviewed was interesting to note. For example,

'Young adults' eye contact with me was either minimal or fiercely intense ... with those who looked away I found myself staring at them ... those who stared at me made me feel uncomfortable and I was unsure of when to look away'.

[Analytic memo 14/06/02]

Scheff (1996) illustrates how failure to conform to the unspoken 'taken for granted' elements of communication and human conduct can 'fundamentally and irretrievably damage conversation',

“Suppose that in your next conversation with a stranger, instead of looking at his eyes or mouth, you scrutinise his ear. Although the deviation from ordinary behaviour is slight (involving only a shifting of the direction of gaze a few degrees, from the eye to the ear), its effects are explosive. The conversation is disrupted almost instantaneously [...] Shock, anger, and vertigo are experienced not only by the ‘victim’ but, oddly enough by the experimenter himself. It is virtually impossible for either party to sustain the conversation, or even think coherently” (p64).

Scheff (1996) is saying that the subtlest of deviances in ‘symbolic’ interaction can have a significant impact on the length of interaction and the experience for both the ‘deviant’ and the recipient. Scheff (1996) also regards the existence of the unspoken ‘taken for granted’ gestures as only recognised when ‘abrogated’ and *“since the culture provides no adequate vocabulary for talking about either the presence or abuse of its invisible understandings, such deviations are considered disruptive and disturbing”* (p65). Furthermore, says Scheff (1996:65), *“the society member’s loyalty to his culture’s unstated conventions is unthinking but extremely intense”*. In developing these ideas, Scheff (1996) argues that others will perceive the infringement of everyday gestures as a threat to their own and society’s ‘status quo’ and the response will be to withdraw from or to modify such behaviour. Comparing this to young adults’ perceptions of *not fitting in* and feelings of ‘alienation’ and ‘not belonging’, it appears that modifying behaviour becomes difficult for two reasons. Firstly, the person with Asperger’s syndrome does not always know what others are expecting, and secondly, there are too many hidden rules that change according to context. Thus the saying ‘it is not what you say but the way that you say it’ bears relevance to this discussion. Young adults did not understand the unconscious meanings conveyed through gestures, whilst others did not understand that young adults did not understand. Thus just as young adults

have difficulty in 'mindreading', others have difficulty in 'mindreading' young adults leading to the joint 'miscommunication of gestures'.

Thus, unless verbally spoken to in a literal and 'unsymbolic' manner, the person with Asperger's syndrome may be either unaware that any communication is taking place, or otherwise misinterpret the situation. Both ways they are rendered vulnerable to 'miscommunication of gestures' that has consequences for their own perception of situations and others' perceptions/responses. For example, when out and about in public places one young adult participant talked about his feeling that people always watched his every move, which made him feel uncomfortable and anxious about going out of the house. In another example, his mother describes how he did not comprehend others' reactions and how this led him to misinterpret their intentions,

"He failed his driving test five times and now won't drive at all ... he says 'If somebody hoots at me, I don't know why they are hooting ... what do they want from me? What am I doing wrong? Why are they out to get me? They are out to get me ... I can't stand it if someone hoots at me ... they are out to victimise me'"

[Sarah, mother of William]

In apparently drawing attention to themselves, young adults have a seeming inability to indicate to themselves the response that their gestures indicated to others. In turn, as mentioned, they seem unable to engage in 'impression management' (Goffman 1959) by controlling the response of others, or by adapting their own response. For the young adult participant who believed people to be staring at him, and for the young adult who thought that, by hooting their car horns, people were victimising him, there appeared to be a breakdown in the shared meaning of gestures between themselves and others. The possibility of not using or understanding everyday gestures in communication is touched upon by Blumer

(1969:9), "*If there is confusion or misunderstanding [...] communication is impeded, and the formation of joint action blocked*". However, Blumer (1969) does not appear to elaborate on this further indicating a problem the study identified in symbolic interactionism that largely ignores the consequences of not communicating 'symbolically'.

Nevertheless, Scheff (1996), in describing people who are mentally ill, does convey the significant social consequences associated with violating society's unwritten social rules of interaction and conduct, however unmeaning and subtle. The reaction of others to people not conforming to the subtle unwritten social rules of communication may explain why young adults often reported feelings of *not fitting in* and perceived themselves 'alienated' from all of society. This then, at least partly, would seem to occur as a consequence of their difficulty in understanding the 'taken for granted' social norms of interaction and behaviour for both themselves and for others communicated through 'symbolic interaction'.

To reiterate this point, people with Asperger's syndrome do not always conduct themselves according to society's unspoken rules and they cannot easily interpret others' actions and intentions through the normal 'communication of gestures.' In turn, the responses of others are based on their own misunderstanding of young adults' actions and intentions. Thus from this perspective, the *not quite fitting in* experiences of young adults appears to be the result of the 'miscommunication of gestures' between young adults and others. This will now be linked to the development of 'self' in young adults with Asperger's syndrome since it is becoming apparent that if one person fails to use gestures appropriately or to

understand others' gestures, then the process of understanding 'self' through the eyes of others is also impeded.

8.3.3 The 'self' and young adults

In this section young adults' sense of 'self' is further explored. Mead's (1934) theory of emergence is drawn upon in more depth to give insight into how the 'miscommunication of gestures' links to the development of 'self'. As mentioned, young adults with Asperger's syndrome had difficulties with understanding the 'self' in relation to others. For example,

"I wonder sometimes who I am. Who is this person in here? Where is he? It's as if sometimes I am outside of my body looking at this guy thinking 'Who is he? What does he think of this or that? It all feels so superficial ... I don't know who I am'"

[Guy]

This participant not only expressed feelings of not knowing who he was but he said that he did not always know his own thoughts and opinions. He described his 'self' as 'superficial', that would seem to imply (from his own perspective) his 'self' lacked depth and understanding. This can be linked to Mead's (1934) concept of the 'reflexive self', whereby having a 'self' involves the ability to reflect on one's mental processes. The implication here is that the young adult participant had some difficulty with this process, although perhaps not entirely as he was reflecting on his own lack of 'self'.

In the study, participants were not directly asked about self-identity but they spontaneously raised the concern. The issue of self appeared to be about understanding 'who they were' in relation to others. Young adults often expressed a desire to be someone else. Thus perhaps unable to take any of the positive attributes of others into their personality in 'taking on the attitude of the other'

(Mead 1934), it felt better just to be someone else. Of course, being unable to take on the 'attitude of others' may also be beneficial and even 'protective' in the face of social adversity, for example, it may be easier not to know if someone dislikes you or does not enjoy your company (an issue that will be discussed later in relation to diagnosis and labelling).

At the heart of symbolic interaction is Mead's theory of the emergence of 'self' that believes the 'self' is a social structure that arises through communication. The widely used diagnostic manuals (World Health Organisation 1993; American Psychiatric association 1994) state core impairments in people with Asperger's syndrome are communication and social interaction. Thus, as already mentioned, according to Mead's (1934) reasoning, impaired communication and social interaction would fundamentally affect the development of 'self'. From this viewpoint, young adults with Asperger's syndrome would be expected to have problems of 'self' arising from 'deviations' of interaction with others and incomplete understandings of how others view them. In taking this further, Mead (1934) describes the 'conversation in gestures' as important to the development of 'self', "*the self [...] arises when the conversation of gestures is taken over into the conduct of the individual*"(p167). He appears to be saying that our 'symbolic interactions' with others, and how we perceive others see us, directly influence our sense of who we are in relation to other people and society in general. How we see ourselves, and the expectations we perceive others have of us also drives our social behaviour, so that the attitude of the other affects the individual's sense of self and behaviour. Thus in conversation, "*the individual can reply with its corresponding gesture and thus the attitude of the other becomes expressed in the self*" (Mead 1934:167). This fundamental view about the self as a product of a person's

interaction with others, and the role of symbolic meanings has importance when considering the experience of people with Asperger's syndrome. This is because these people, as suggested by the very nature of their diagnosis, have core impairments in their interactions with others and they are impaired in their ability to infer the attitudes of others (Baron-Cohen 1991, 1995). In other words they are 'less able' to 'converse in gestures', and from Mead's perspective are less able to 'take on the attitude of the other' so important to the development of 'self'. However, young adults were not totally 'unaware' of their position in relation to others, even if they did not 'quite' understand the full meaning underlying others' behaviour or interaction. Thus they did demonstrate some awareness of 'self', even in their perceived lack of self. As mentioned, several young adults questioned their sense of 'self', but, by the very process of questioning this, they were demonstrating an awareness of their difficulties or 'differences' that suggests some awareness of 'self'. For example,

"All I can reason is if people have it severely they don't realise there is a problem ... they are blissfully unaware. But for us you realise there is something quite wrong [...] and it's the awareness that's the killer"

[Ben]

In this excerpt, 'awareness' of difference is being contrasted to people with Kanner's autism who are perceived as 'blissfully unaware' of their differences. Here the participant appears to be suggesting it is worse having an awareness of a different 'self' than no awareness of 'self' at all. It is this 'different self' that will now be expanded upon in relation to symbolic interactionism.

8.3.4 The 'I' and the 'me' self

This section discusses young adult and parent participants' descriptions of 'self' in comparison to Mead's conceptual distinction between the 'I' self and the 'me' self. The position of parents is interesting to note because the 'I' self in parents' accounts seemed hidden as they appeared to combine their own experiences with their son or daughter's experiences. To Mead (1934), the 'me' is the socialised self made up of the 'internalised attitudes' of others as experienced in the early years of life and the 'I' is the unsocialised self, an 'assortment of personal desires, needs and dispositions'. In order to make better sense of this distinction in writing about the 'me' self, I use the term 'me and you' self. This helps to conceptualise the 'me' in relation to others.

In young adult participants, it is suggested that the unsocialised 'I' seemed more apparent than the social 'me and you' self. Mead's distinction between the 'I' and 'me and you' provides some possible clarification for why young adult participants appeared to be so self-absorbed, and why their accounts apparently lacked concern for others. The lack of empathy towards others included those who played significant roles in their lives, that is, parents. Withstanding variation between young adult participants, at the centre of all of their interview accounts was an overwhelming focus on themselves. The talk of young adults centred on the 'I' self and they seemed to be lacking in the concept of the social 'me and you' self. Consideration for the circumstances, thoughts and feelings of others was markedly absent in their accounts. For example, one young adult purported to reject his family but made no attempt to think about how they might feel about his negative words or actions towards them. However, he also had high expectations of what they should be doing for him. From his perspective he was their son and they owed

him much, but any reciprocity of concern for them was absent. This young adult bore no obvious feelings of affection or responsibility towards his parents; on the contrary he appeared to resent them. For example,

"My parents should pay for me [to go to University] but instead since they got divorced they have spent the money on buying two houses ... they should do more to help me [...] I am disgusted that they have two houses ... they should have spent the money on me ... I am their son".

[Nick]

Following this interview I noted in a memo,

'Nick sounded so very indignant and angry when talking about his parents that I couldn't help but begin to feel a bit alarmed at his strength of feelings against them' [Interview Memo 19/01/00].

It seemed that, from the perspective of young adult participants, life stories, experiences, objects, and people were all talked about from the one point of view, the 'I', rather than from the incorporated perspectives of others, the 'me and you'. Thus another hypothesis emerged: young adults' self-absorption may be due to a more developed sense of 'I' than 'me and you'. Consistent with this and concurrent with Baron-Cohen's (1991, 1995) theory of 'mindblindness' was young adults' sense of 'self' that appeared to lack understanding of other people's perspectives, feelings, desires and emotions.

In maintaining a symbolic interactionist perspective and simultaneously trying to capture young adults' sense of 'alienation', their difficulty in socially and psychologically locating the 'self' might be a consequence of an 'unsocialised self'. This provides a possible explanation for why so many young adult participants reported feelings of difference, alienation, aloneness, and ultimately of *not quite*

fitting in. It might also explain why parents felt their relationship with their son or daughter was often one sided. For example,

“He saps me dry ... he drains me completely ... gives nothing back”.

[Jill, mother of Martin]

In contrast to young adults' 'I' over 'me and you' selves, it is argued that in caring for their son or daughter with Asperger's syndrome, many parents give up or forgo their 'I' self for the 'me and you' self. For example,

“I don't think anyone can know how much living with a person with Asperger's takes of the self”.

[Jenny, mother of Jack]

This parent was suggesting that her son had taken a part of her 'self', illustrating how caring for a young adult can affect parents' own sense of 'self'. One way in which young adults 'took' from parents' 'self' could be said to be in the lack of a reciprocal relationship. The literature on 'caring' often indicates the existence of a 'caring relationship' between the carer and the person being 'cared-for' (Finch 1989; Morris 1993; Read 2000). Finch (1989) highlights the notion of reciprocity within family assistance and in a study of parents caring for 'adult children' with severe physical or sensory impairments, Read (2000) highlights the strength in the relationship between the mothers and disabled adult children as well as how the mothers received 'emotionally' from the relationship. Furthermore, says Read (2000:88),

“While many parents and children may feel a close tie that lasts a lifetime, few are bound together as intimately as many of the mothers and their disabled sons and daughters”.

However, in contrast to this view of the relationship and intimate bond between the parent carer and disabled son or daughter, the caring relationship between parents and young adults in the current study seemed one-way. For example,

“He knows everybody’s birthdays but he never thinks to send anyone a card including me. I once said to him it would be nice if he gave me a card ... after all he wouldn’t like it if I didn’t give him one ... and he told me it was a waste of money ... he wasn’t joking”.

[Amanda, mother of Paul]

The above extract is an illustration of the lack of reciprocal give-and-take connection between parent and young adult. Whilst in many situations parents might expect their ‘adult children’ to ‘take more than give’ (emotionally and practically), they may also expect something back from their son or daughter in time, thought and action, such as the emotional reciprocity described in Read’s (2000) study. However, young adults seemed to give very little of their ‘selves’ whilst it appeared that parents were being expected to give of themselves and their resources ‘self-lessly’. Thus it seems that parents’ lives often revolve around their son or daughter with parents expecting and receiving little in return. This was illustrated in how parents and young adults lived together. For example:

“I live with him rather than him with me ... it wouldn’t work any other way [...] my life is moulded around his”.

[Marie, mother of Robert]

The concept of parents ‘moulding’ their own lives around their son or daughter recurred in several parents’ accounts. This process began in early childhood and continued as their son or daughter grew into adulthood. Whilst this might be true of many parents in general, it was the extent to which parents in the study adapted their lives to meet the needs of their children and the continued nature of this that ultimately set them apart from other families. Thus parent participants ‘adapted’ to their son or daughter and they ‘indefinitely’ gave up their own wants and desires for the benefit of their son or daughter with Asperger’s syndrome. For example,

"We haven't been on holiday for years ... he doesn't like travelling and we can't leave him on his own....so we don't go anywhere".

[Jenny, mother of Jack]

From a symbolic interactionist perspective by 'adapting' or 'moulding' themselves around their son or daughter, parents allowed the 'me and you' self to preside over their own personal needs, desires and ambitions. They appeared to have suppressed the 'I' in favour of the empathetic 'me and you' and they had placed their adult child's needs and desires above their own. Another example of the prominence of parents' 'me and you' over 'I' selves was the way in which their accounts did not separate their own lives from their son or daughter's. Even when prompted to talk about their own feelings, emotions, hopes and ambitions, parents seemed unable to disengage their own *not quite fitting in* experiences from those of their son or daughter. Conversely young adults barely mentioned their parents during the interview, and when they did, they tended to lack regard for their parents' thoughts or feelings within the context of their dialogue. As people being 'cared-for', young adults seemed unable to recognise that their parents were doing anything out of the ordinary for them. This would seem to be in part because of their self absorbed 'I' over 'me and you' selves but also in part because parents acted 'covertly'. Some parents consciously hid the things that they were doing from their son or daughter in an attempt to boost their son or daughter's sense of 'self' worth. For example,

"I don't tell her everything I'm doing because I want her to feel more in control ... to feel better about herself".

[Julie, mother of Naomi]

In addition, parents wanted to help their son or daughter to 'move on' and try new things in life. For example,

“He’s his own worst enemy in terms of moving on and developing his life because he’s so resistant to change and afraid I think of taking on new things that he won’t do it unless he can really be persuaded or tricked into doing it”.

[Carol, mother of Carl]

Thus there was a degree of ‘covertness’ in the role that hid what parents were doing for young adults, and involved placing the needs of their ‘adult child’ before their own. Furthermore, it is argued that parent participants took on more and more of the ‘me’ as their son or daughter grew into adulthood. This is in contrast to parents of ‘normal’ adult sons and daughters who are perceived as ‘letting go’ of their responsibilities for their growing children, allowing themselves greater freedom and independence. Thus, whereas in the context of ‘normal parenting’ when children reach adulthood most parents can resume a greater ‘I’ self, the lives of parent participants continued to revolve very much around their son or daughter. From parents’ perspectives this seemed likely to continue indefinitely. For example,

“I’m 45 now and I had my children young [...] I did it consciously so that when I was older I could do things that perhaps I wanted to do and I envisaged myself travelling at this age and I can’t because I always have to think about Martin at home”.

[Jill, mother of Martin]

Thus, it is hypothesised that as young adults develop a greater ‘I’ than ‘me and you’ self, parents’ ‘me and you’ overshadows the ‘I’. For parents this became more obvious at the stage in life when other parents were able to begin thinking about their own self-interests, desires and ambitions. Whilst the ‘burden’ of caring is well documented (Twigg and Aitkin 1994; Campling 1996; Read 2000), it could be the case that all carers take on a greater degree of ‘me and you’ over ‘I’, it is suggested here that the lack of reciprocity and young adults’ unreserved sense of ‘I’ over ‘me and you’ further contributes towards a greater burden of care for this group of parents. Furthermore, the ‘covertness’ of parents’ roles and the non-obvious nature

of the disability that leads to a lack of support formally and informally all add to this being a particular feature of these parents' sense of 'self'. There seemed to be few of the rewards that others report can be found in emotional relationship with a dependent 'adult child' (Finch 1989; Read 2000). Unlike other parent carers who may at the very least receive some emotional reward for their endeavour through a reciprocal relationship, these parents did not receive in return in this way, nor did many of them expect to. Thus parent participants did *not quite fit into* the normal roles of parenting non-disabled 'adult children' nor did they *quite fit into* the role of 'carer' caring for an obviously disabled child in adulthood.

8.3.5 The 'I' and potential for achievement

There is a danger in perceiving the phenomenon of *not quite fitting in* as an exclusively negative consequence of living with Asperger's syndrome. There is an equal danger in viewing the 'I' over 'me and you' self of young adults as inherently detrimental. This is further theoretically explored in relation to the strengths in having a different way of conceptualising the world and objects within it. Mead (1934) did not specifically refer to a greater 'I' over 'me and you' self, but he did highlight the potential strength of the 'I' self, which can be linked to Asperger's (1944) notion of 'autistic intelligence' as an 'evolutionary difference' necessary for the advancement of society. Wing (2005:199) ponders Asperger's viewpoint,

"It is possible that high functioning people with Asperger's syndrome have always been responsible for innovative ideas that have moved the world on, since they are not bound by conventional socially accepted wisdom".

In the current study, whilst overall young adult and parent participants appeared to view the experience of having Asperger's syndrome negatively, there were some

who discussed this 'way of being' as, at least potentially, beneficial. As one mother explained,

"We tend to think of this as a disability that is unnatural and needs to be cured. But I feel we should be looking at how we can get hold of the unique 'spirit' in James and allow him and others like him to grow... to still be different but 'successful different'. To get hold of what they've got and let them grow in an environment where different is not necessarily seen as bad or negative ... just different ... to let them be themselves and ... blossom".

[Claire, mother of James]

This mother appeared to be putting forward a case for viewing Asperger's syndrome 'differently', as 'successful different', rather than as a deficit that needs to be cured. Interestingly, some young adults even expressed a desire and 'need' to be different. For example,

"I like being different...I am proud to be different [...] I am who I am...why should I want to be anything else? I am proud to be different. I don't want to be like others"

[Nick]

In the next example, the participant talked about his search to 'achieve his real genuine self' by relating himself to famous 'mad' people to whom he could relate,

"I know that to achieve my real genuine person I have to go to extreme depths [...] that's why I relate to people who are famous ... but not impersonators. I'm trying to get an element of what they are about and relate it to myself... maybe they had the same problem as myself ... these mad people ... mad people are in fact real individuals rather than sheep ... they are the shepherds"

[William]

Here the participant talked about the psychological depths he takes himself to in the search for his 'real' self. He related himself to famous 'mad' people, whom he perceived as 'real individuals'. This links to Storr's (1988) description of famous people of 'genius' who had exceptional creative power, for example, Rene Descartes, Isaac Newton, Sylvia Plath, Immanuel Kant and Ludwig Wittgenstein. Such people, says Storr (1988), were more preoccupied with what went on in their

own minds than with the welfare of other people, and are often thought of as peculiar, odd human beings who did not share the pains and pleasures of the average person, in that they preferred solitude to social relationships. In discussing their 'genius' Storr (1988:81) refers to their creative 'originality',

"Originality implies being bold enough to go beyond accepted norms. Sometimes it involves being misunderstood or rejected by one's peers. Those who are not too dependent upon, closely involved with, others, find it easier to ignore convention".

Although Storr (1988) is not discussing people with Asperger's syndrome per se, similarities can be drawn between the people he describes and some features of the young adult participants' lives. Like Storr's (1988) famous individuals, young adults described themselves as being misunderstood and rejected by others. Some felt socially excluded and others isolated themselves, preferring to be alone. They lacked involvement with others, and found it difficult to conform. Storr's (1988) concept of 'originality' also links to Asperger's (1944) thoughts on 'autistic intelligence'. Asperger (1944) suggests that 'originality' can emerge from the autistic people's unique form of intelligence. In Asperger's (1944) view there are some possibilities *only* available to the person with Asperger's syndrome. Not only are autistic people capable of producing original ideas, says Asperger, their ideas can *only* be original because they are not the 'assimilated' knowledge of others. This supports the view that people with Asperger's syndrome do not take on Mead's (1934) concept, the 'generalised other'. Asperger (1944:74) further states,

"Distance from the object is the prerequisite of abstraction of consciousness, and of concept formation. Increased personal distance which characterises autistic individuals and which is also at the heart of their disturbed instinctive affective reactions, is, in a sense, responsible for their good intellectual grasp of the world".

Thus, like both Storr (1988) and Wing (2005), Asperger (1944) associates the individuals' distance from society to the capacity for original thought. He believes impairment and originality are intertwined, *"just as, in general, somebody's good and bad sides are inextricably linked, so the special abilities and disabilities of autistic people are interwoven"* (p70). This concept of autistic originality is further supported by Mead's (1934) advanced conceptualisation of the 'I' self whereby he asserts that the 'I' is also the source of *"novelty and originality"* (p209). He further argues that it is this *"novelty of interrelations with the environment that leads to endless change in the social world"* (p217) and *"it is in the individual reactions of the individual, the 'I' [...] that important social changes takes place"* (p216) as in the case of *'great leaders, scientists, investors, and artists'* (p216). Here Mead (1934) is saying that when the effects of the 'I' are 'profound', the 'individuality' of the 'I' is important, and it is in this way that 'individuals' rather than society influence advancements in the world.

Thus, in this thesis it is argued that the hypothesised 'I' over 'me' in young adults is a potential strength. This supports one mother's call that society (including families, schools, professionals, communities) should be striving to help those with Asperger's syndrome to achieve 'successful difference', as opposed to forcing them to conform. Drawing on the argument thus far, we as a society perhaps should recognise the phenomenon of *not quite fitting in*, and seek to liberate potential talent and original thought, rather than constrain or limit such individuals by rigidly expecting them to conform to developmental and social norms of behaviour. Such potential is highlighted in some of the parent accounts,

"He was always very artistic and took a blacksmith course ... he was the best on the course and a professional blacksmith ... a famous professional blacksmith ... one of the best in Britain ... wanted him to be his apprentice ..."

and he went but was too stressed and anxious all the time and became quite ill ... so that was it”.

[Sandra, mother of Matthew]

In addition to parents recognising potential, some young adults also acknowledged their ability. For example,

“I have the ability, I’m quite clever ... I mean academically ... I always did well ... and I have achieved ... its just all the anxiety and all the other stuff that gets in the way”.

[Richard]

The potential may therefore be present in young adults with Asperger’s syndrome to achieve personally and perhaps even influence the development of society through their originality and ability to transcend ordinary thoughts and conventions. However, this did not appear to be the reality for young adult participants in the study. For most they appeared to be caught between wanting to fit in and trying to cope with the stresses and anxieties of trying to fit into a seemingly intolerant society. Whilst their ability hid and in some cases compensated for their difficulties, these social difficulties also impeded their ability and potential for achievement. Nevertheless, Asperger’s (1944) belief suggests that young adults may be capable of great achievements that are only available to them, not most others, as seen in history’s great thinkers, artists, as well as those responsible for recent advancements in the development of information technology and the internet. It is hypothesised that these achievements are not just of value to the individuals who have Asperger’s syndrome but also to the society in which they live, and sometimes to society in general. This leads to another important observation by Asperger (1944:89), *“Autistic people have their place in the organism of the social community.”* In this sense, people with Asperger’s syndrome *do fit in*, and the challenge to professionals is to adopt an approach to enable them, and wider

society, to regard such differences as potential strengths rather than a mind 'disorder' or 'deficit', or simply as deviant or delinquent behaviour. Further study in this area could usefully take a 'salutogenic' approach as recommended by Antonovsky (1996), in exploring the positive coping attributes of people with Asperger's syndrome and their families. It could also examine possible ways of strengthening the 'sense of coherence' in these families, that is, the 'comprehensibility, manageability, and meaningfulness', of life. For example, one young adult discussed his lack of achievement at school in relation to the meaningfulness of the work/activities,

"I was quite clever at school, I always came 3rd in tests, but the same boy always came 1st. I don't like competition ... since the same boy always came top it was a forgone conclusion and why bother? I couldn't see the point. It was the same with sport, it was meaningless to me so why do it?"

[Andrew]

Another young adult talked about his perception of socialising, he could not understand why people want to get together simply for each others company,

"A lot of people say to have a good time you go out and socialise right? Well for me that is a nightmare ... my good time ... to have a good time for me is to get away from that ... to get away from that situation ... I am totally the opposite ... it just puzzles me you know why they would want to do it ... it is suicide... it is personality suicide."

[William]

Here it is apparent that young adults' behaviour is related to their sense of meaningfulness of the activity being presented, however, their level of understanding or perception of the situation do not always *quite fit in* with social norms or usual expectations. This leads to the next issue, the meaningfulness of the diagnosis to young adults and their parents.

8.4 Diagnosis and labelling

In this section, issues of diagnosis, also commonly referred to as 'labelling', are discussed. Classic and contemporary symbolic interactionist texts in the fields of social psychology (Goffman 1959, 1963; Porter 1998), health behaviour (Becker 1963), and mental health (Scheff 1966, 1996; Rosenhan 1996) are being drawn on to inform the discussion concerning 'labelling' in the context of Asperger's syndrome.

In the present study, the diagnosis of Asperger's syndrome was found to raise more issues for parent participants than for young adults. The findings analysed from a symbolic interactionist perspective, led to the hypothesis: young adults demonstrate ambiguity towards their diagnosis as a result of their 'different' way of viewing the 'self' in relation to others. Blumer's (1969) three basic premises of symbolic interactionism are drawn upon in the illustration of the contrasting views of young adult and parent participants towards diagnosis and labelling. The discussion then focuses on a specific aspect of symbolic interactionism, namely labelling theory, as popularised by Goffman (1959, 1963) and Becker (1963). This is related to the field of health through the discussion of Thomas Scheff's (1966, 1996) application of labelling theory to mental illness. Throughout the discussion the relevance of labelling theory to the diagnosis of 'Asperger's syndrome' will be considered in relation to the experience of *not quite fitting in* for both young adults and their parents. The discussion begins with consideration of the meanings, or lack of meaning, which young adult participants attached to their diagnosis.

8.4.1 The meaning of diagnosis to young adults

In this section, the accounts of young adults are discussed in relation to how they perceived the diagnosis of Asperger's syndrome and the apparent meaning attached

to this diagnostic 'label'. Generally during the interview, young adult participants did not discuss their diagnosis spontaneously. On the contrary, when questioned about their diagnosis, many made statements verging on the dismissive. For example, "*Oh the diagnosis ... yes well ... I don't really think about it much ... it's only mild for me*" [Sebastian]. Another young adult replied, "*they say I have Asperger's*" [Tim], said in such a disinterested way that it appeared as if he had passively accepted this view that others had expressed about him, but to him it had no real meaning. This may be linked to the earlier suggestion that young adults did not incorporate the views of others into their sense of self, also supporting the hypothesis that the 'I' had greater strength over the 'me and you' self. At perhaps the more intense level, one participant described his absolute rejection of the 'Asperger' diagnosis. For example, "*I don't need a psychiatric label to accept who I am or to understand myself ... I do not want to be labelled in this way ... I reject the Asperger's label*" [Nick]. This young adult was the only participant to express such a negative view of the diagnosis. Nevertheless, even in his rejection of the diagnosis, this participant's reason for this seemed to be its lack of meaning to *him* not the meaning to others or the impact on him as a consequence of others' views. This then supports the hypothesis of a poor sense of self in relation to others.

The lack of reference to the diagnosis by almost all young adult participants may have been because they had little to say about it or that it held little relevance for them, in respect of the impact on their lives, either positively or negatively.

Reflecting on this I comment in a memo,

'In most accounts young adults do not mention their diagnosis. It was as if it was unimportant, irrelevant. Does this mean they had not realised any impact from the diagnosis, or that there was no real impact?'

[Analytic Memo 1/12/02]

In considering the issue of young adults' indifference to their diagnosis, the premises of symbolic interactionism (Blumer 1969) are drawn upon. First, Blumer (1969) argues that human beings act towards things on the basis of the meanings that the things have for them. These 'things' might be physical objects, other human beings, ideals, institutions, categories of people, activities and situations. In this instance, the diagnosis of Asperger's syndrome becomes the 'thing'. Secondly, according to Blumer (1969), 'meanings' are derived from the social interaction with others. Thus if social interaction is impaired, the 'meanings' attached to things will be affected. Here it can be inferred that young adults may not appreciate the attitude of others towards their diagnosis and therefore, the meaning they attach to the diagnosis is unaffected by the views of others. As a consequence, young adults may perceive the diagnosis as 'value free' rather than 'value laden'. The diagnosis becomes an 'object' that may or may not serve to explain their differences, but also, crucially, for young adults it appears to hold no stigmatising power.

This response to being given a diagnosis is in conflict with traditional theories of labelling (Goffman 1963; Becker 1963; Scheff 1969) and the social model of disability (Oliver 1991, 1993, 1998), from which the processes of labelling, medical diagnoses, and the language we use, are viewed as fundamentally damaging to the individuals' sense of self and to their life chances. Becker (1963) built his theory of labelling deviance from two symbolic interactionist premises. First, that our self is the result of the symbolic interpretations that emerge from our interaction with others, and second, that the meaning we attach to an object is the result not of the innate qualities of that object but of the active interpretations that others apply to certain individuals. In essence, Becker's position is that whether an act is deviant or

not depends on how other people react to it. Thus, perhaps, young adults felt ambivalent to the diagnosis because they did not recognise that the diagnosis affected others interpretations of them. Similarly, Goffman (1963) also argued that people in society are labelled as deviant not according to their innate attributes but instead according to the symbolic interpretations of those supposed attributes that others construct. This, argues Goffman (1963), leads to 'stigmatisation' of the person so labelled. Thus, the perceived stigmatising effects of labelling may be minimised for young adults, perhaps as a result of 'mindblindness' (Baron-Cohen 1991, 1995). Beneficially, 'mindblindness' may act as a buffer to the negative affects of the diagnostic label. Therefore in the case of young adults with Asperger's syndrome, the impact of the diagnosis may be less than for people with other psychiatric diagnoses, who are aware of the possible effects of that 'label' on the attitudes and actions of others.

In the field of mental health studies (Scheff 1966, 1996; Rosenhan 1996) there exists a persuasive argument that a medical diagnosis is a form of labelling that can act as a powerful form of control. This, some argue, can fundamentally influence a person's life course in terms of how they view themselves and how others respond to them. In drawing heavily upon Goffman's (1963, 1968) concept of stigma and of a deviant career, Rosenhan (1996) argues that it is the label itself that influences how mental health patients and others perceive and treat him or her,

"A psychiatric label has a life of its own. Once the impression has been formed that the patient is schizophrenic, the expectation is that he will continue to be schizophrenic...such labels, conferred by mental health professionals, are as influential on the patient as they are on his relatives and friends, and it should not surprise anyone that the diagnosis acts on all of them as a self-fulfilling prophecy." (p78).

However, in contrast with these views, the hypothesis here is that some young adults with Asperger's syndrome may not suffer the same level of negative effects due to their lack of ability to understand and perceive how a label may influence other people's thoughts and opinions of them. Thus the diagnosis of Asperger's syndrome may not, as Rosenhan (1996) suggests, have 'a life of its own' or have any influence over young adults' view of the self. An exception to this might be the young adult participant who rejected the label of Asperger's syndrome. However, whether or not young adults are aware of their diagnosis, the diagnosis/label of Asperger's syndrome may still impact on how others perceive them and thus how others act towards young adults. This may be potentially helpful or harmful. For example, helpful through easier access to service provision, or harmful by resulting in negative discrimination, for example, through avoidance or rejection (such as blocking career opportunities) or in limiting a person's potential for achievement through reduced expectations. Further investigation is required to understand and know more about the potential costs and benefits of diagnosis.

8.4.2 The meaning of diagnosis to parents

Contrary to the view held by the young adults, parents (in general) seemed to welcome their son or daughter's diagnosis of Asperger's syndrome. For example,

"It's been a great help [diagnosis] ... since we've known is the only time Daniel has received help ... he's never had the right help until we've had the diagnosis."

[Judy, mother of Daniel]

It is interesting to note that this parent's use of the phrase 'we've had the diagnosis' also encompasses the parent supporting further the 'me and you' hypothesis relating to parents. This might also be related to the level of help received, whereby without

help, parents bear the greater burden of responsibility. This is illustrated in another example,

"I only wish I'd known when he was at school ... I think it could have helped me when talking about his problems with the teacher".

[Mary, mother of Philip]

Parents seem to suggest that had their son or daughter received a diagnosis earlier it might have helped them in arguing for greater support and understanding for their child. This view is supported by Stirling and Prior (1999) in a report for a UK charity, 'The National Autistic Society'. In this report, the value of diagnosis for accessing services is argued as an essential key to 'opening doors' to available support,

"In the case of autism [and Asperger's syndrome] getting an accurate diagnosis is the key required to open the door to the specialised support families and people with autistic spectrum disorders need [...] without a diagnosis, parents, people with autism and their families are almost literally shut out and disempowered [...] shut out from the services and support that could really improve their lives in tangible, practical ways" (Stirling and Prior 1999:3).

Stirling and Prior (1999) argue that without a diagnosis parents are 'disempowered', seemingly 'powerless' in the face of ignorance and bureaucracy to access services. In addition to the lack of access to support services, parents also discuss how in the absence of a diagnosis, 'other' negative labels had been attached to their son or daughter throughout their lives. For example, naughty, lazy, disturbed, shy, stupid, rude, and aggressive. Thus, parents argued that in the absence of a diagnosis, others still labelled their son or daughter as different in negative ways as others perhaps tried to make sense of behaviours and actions that *do not quite fit in* with social norms. This point is paralleled in the potentially tragic consequences of society not understanding behaviour and the motives behind actions as powerfully played out in the Camus' (1942) fictitious character of Meursault. He was labelled a murderer

even though he acted in self-defence when killing a man, because others could not understand his lack of emotion or expressed remorse. Meursault, however, was not remorseful because he believed he acted in accordance with the law, and he did not modify his behaviour to feign remorse, because he did not comprehend the consequences of his predicament. Others could not understand his behaviour and he could not understand their questioning of his account. As a consequence he was mislabelled by others, unfairly judged and ultimately condemned to die.

Thus judgemental labels would seem to be applied to people who do not conform to social norms of behaviour, interaction and emotion, and the negative effects of labelling occur regardless of a diagnosis. The diagnostic label may even help to alleviate inappropriate labels being applied. In addition, parents found they were often labelled, typically as being poor parents or as having inadequate parenting skills. For example,

“I do think it would have been better if he had had a diagnosis when he was little; we could have sheltered him from some of the negative things [...] His problems wouldn’t have been always put down to me, ‘single parent syndrome’.”

[Judy, mother of Daniel]

This parent was arguing that without the diagnosis not only was her son being labelled negatively but as a lone parent, she, or ‘single parent syndrome’, was being blamed for his difficulties. Thus as others attempted to make sense of the child’s behaviour, parents were blamed and so labelled as ‘bad parents’ or as having low parenting ability, which is reminiscent of dated views of autism as a reaction to maternal pathology (Bettelheim 1955). Hence parents were being judged by virtue of being parents, rather than their actual parenting abilities. Goffman (1963:43) regards this as a ‘courtesy stigma’ *“whereby family members are obliged to share*

some of the discredit of the stigmatised person to whom they are related'. From this it can be argued that parents may benefit from being given a diagnosis for their son or daughter's behaviour as the blame for this behaviour can be redirected away from them (parents and young adult) onto the objectified condition 'Asperger's syndrome'. Thus a diagnosis may act as a buffer to parent(s) as well as to young adults, to counter stigmatising processes (the negative views of others) by providing an explanation to others of *not quite fitting in* behaviour and interactions.

8.4.3 Perceived costs and benefits of a diagnosis

This section discusses the perceived potential costs and benefits of a diagnosis of Asperger's syndrome to young adults and parents. The conflict between the perceptions of the costs/benefits to young adults and the costs/benefits to parents is also discussed.

As has already been suggested, young adults may have been protected from the stigma of their 'diagnosis' through 'mindblindness'. Thus the potential benefits of a diagnosis (providing understanding and insight, information, access to services and support networks) may outweigh the potential costs (stigmatisation, discrimination, reduced opportunities, exacerbating differences). From parents' perspectives, the advantages of diagnosis may be more important than potential disadvantages. However, it may be that parent participants are not representative of all such parents. The findings of the present study may reflect a sampling bias in that parents who are not in favour of a diagnosis might have been difficult to identify as they are unlikely to be members of a parent support group or be in contact with an autism related charity (particularly as parents may not want to associate Asperger's syndrome with popular notions of autism). As discussed by

some parents, one potential conflict of the diagnosis lies in them wanting to help son or daughter to feel 'normal' as opposed to highlighting that they are different.

For example,

"I've found it difficult to discuss this [diagnosis] with him because on the one hand I want him to understand what his difficulties are and to understand that it's O.K. to have those difficulties because it's being addressed and lots of other people have these difficulties. But I don't want him to feel too disabled, or not too different. I don't want him to feel he's an oddity because I'm trying to make him part of society and I'm trying to say it's O.K. to be like this and you know everybody is different ... so it's a bit of a conflict really".

[Carol, mother of Carl]

Here the parent identifies the wider question of diagnosing conditions like Asperger's syndrome in a society that purports to embrace diversity. Thus, the question raised is whether or not a diagnosis narrows the boundaries of normality, or whether it serves to foster a more inclusive philosophy by helping affected people to integrate into society by providing greater understanding, support services and wider opportunities. Although, some parents were fearful about making their son or daughter feel even more different from others, the experience of young adult participants did not altogether bear this out. From young adult's accounts, the diagnosis did not appear to be associated with intensifying their differences. The majority of young adult participants reported always having felt different and the diagnosis did not seem to have an obvious impact upon their stance. However this question needs further investigation to understand more fully the potential costs and benefits to people who are told they have Asperger's syndrome.

8.5 Summary

In this chapter the argument has been that the phenomenon of *not quite fitting in* applies to both young adults with Asperger's syndrome and their parents, albeit to differing dimensions. The discussion aimed to 'theorise' the findings from the

analysis of participants accounts by examining the phenomenon *not quite fitting in* in relation to a range of literatures including theoretical, empirical and biographical. In doing this, the findings were compared to the theoretical perspective of symbolic interactionism derived chiefly from G.H. Mead's (1934) work on 'self and society', and Blumer's later related work (1962, 1969) about symbolic interactionism. Through the integration of the findings within the perspective of symbolic interactionism, an interrelated set of hypotheses emerged to conceptualise the phenomenon of *not quite fitting in* for young adults with Asperger's syndrome and their parents. Thus, from a symbolic interactionist perspective, it is hypothesised that,

- young adults did not fully engage in early socialisation processes involving social role-play (essential for gaining understanding of both 'self' and 'others'), thus,
- the experience of *not quite fitting in* for young adults with Asperger's syndrome begins with the lack of early social play; necessary for learning skills of 'reciprocity, co-operation, and to begin to see oneself from the stance of the other'. Poverty of social play is further linked to,
- the 'miscommunication of gestures', that is, the lack of comprehension and, use of 'symbolic interactions' in communication – thus the recognition of a relationship between a 'sign' and its referent. This also links to theories of mindblindness, 'the ability to infer other people's thought, feelings and emotions (Baron-Cohen 1991, 1995), and in turn, impedes,
- the unfolding capacity for 'self awareness' in the form of reflecting on the 'self' from the perspective of other people. Thus, in young adults with Asperger's syndrome,
- the unsocialised 'I' self incorporating, an 'assortment of personal desires, needs and dispositions' (Mead 1934) develops over the socialised 'me and you' self that incorporates the perspectives of others. In compensating for their son or daughter's difficulties, parents, in contrast,
- allow the unselfish 'me and you' self to 'take over' from the 'I' self, thus placing the needs of their son or daughter above their own personal needs, ambitions and desires.

These hypotheses contribute towards an understanding of the phenomenon of *not quite fitting in* for both young adults and parents. They also shed some light on the issue of 'diagnosis and labelling', towards which young adults seemed ambivalent whilst parents generally welcomed it. It is suggested that mindblindness, and the impaired capacity to see how others view oneself (Baron-Cohen 1995), may act as a buffer to the effects of labelling and stigmatisation (Goffman 1963). From parents' perspectives the 'social barriers' and negative attitudes exist in the absence of a diagnosis rather than as an inevitable consequence of the diagnosis. Parents, and organisational advocates for people with autism spectrum conditions, such as The National Autistic Society (Stirling and Prior 1999), appear to welcome the diagnosis of Asperger's syndrome, arguing it 'opens the doors' to understanding and support that can help to alleviate social barriers. Many young adults, however, seem not to perceive any costs or benefits to being given a diagnosis. Thus its impact upon them seemed minimal and at times irrelevant. Finally, some parents were cautious about being given a diagnosis, in that they did not want to exacerbate feelings of difference in their son or daughter, but at the same time wanting to make every effort to help them to 'fit in' better to society. Thus in conclusion, the issue of whether or not to diagnoses people with Asperger's syndrome remains complex. Whilst theories of labelling (Becker 1963; Goffman 1963; Scheff 1966, 1996; Rosenhan 1996) and discourses from disability about the language we use and its 'disabling power' (Ryan and Thomas 1980; Oliver 1998) add to the discussion of issues of diagnosis and Asperger's syndrome, they do not appear to account adequately for the experiences of young adults, parents or the phenomenon of *not quite fitting in*, indicating the need for further research in this area.

Taking into consideration the theoretical hypotheses presented in this chapter, the next chapter will conclude the study by setting out the implications for primary health care practitioners and suggestions for further study.

Chapter nine

Concluding chapter

*“We shall not cease from exploration
And the end of all our exploring
Will be to arrive where we started
And know the place for the first time.”
(T.S. Elliot: ‘Little Gidding’)*

9.1 Introduction

The purpose of this final chapter is to set out the ways in which the study has added to the growing body of knowledge concerning Asperger's syndrome and link this into community health care practice. Some suggestions for policy and practice will be made although it is not intended to provide the answers to how health professionals should respond to the challenges raised in the thesis that face participants with Asperger syndrome and their parents, but rather raise their awareness of this 'hidden population' and stimulate areas for discussion and further research. The chapter will start with a brief summary of the study findings, followed by the lessons learnt, strengths and limitations of the study, the implications for community health care practice and finally, areas for further research will be identified.

9.2 Summary of the study

The study used grounded theory methodology to explore the experiences of young adults with Asperger's syndrome and their parents. The study aimed to do this by being 'open' to the main concerns of participants, thus allowing the data to direct the course of the study (Glaser 1998). Furthermore, the objective central to the study was to account conceptually for the main issues and concerns arising from the data. To achieve this, the emergent finding of the phenomenon *not quite fitting in* was theorised through integrating the findings with other biographical, empirical and theoretical literatures. In the latter stages of the study, a symbolic interactionist perspective emerged as a framework that could explain further the phenomenon of *not quite fitting in*. From this a number of interrelated hypotheses emerged to

‘account conceptually’ for the phenomenon *not quite fitting in* for both young adults and their parents, as set out in chapter eight.

9.3 Lessons learnt

A number of lessons were learnt throughout the course of the study, and this section addresses both the strengths and limitations of the study.

In seeking out the views of young adults with Asperger’s syndrome and their parents, the study addressed some major gaps in the current research literature by:

- focusing on ‘adults’ as opposed to the burgeoning research on children with autism spectrum disorders
- understanding the perspectives of those affected by Asperger’s syndrome by interviewing participants with Asperger’s syndrome, and their parents, both largely neglected in the research literature
- using a qualitative approach to address the above gaps, in an area that is currently dominated by quantitative related studies

The study concerning adults with Asperger’s syndrome presented a number of ethical and practical dilemmas that have been discussed in detail in chapter four. The main issues arising centred around accessing participants, interviewing young adults, third party information from parents, confidentiality, informed consent and the participant-researcher relationship including dynamics of power and gender. In addition, the roles of an informal advisory group and supervision were reflected upon, as well as the impact on me as the researcher. Given the dearth of research involving young adults with Asperger’s syndrome, the issues documented in chapter four also contribute new knowledge.

The main limitation of the study lies in the 'representativeness' of the sample and subsequently the generalisability of the findings. This is because the sample group were accessed through a 'convenience' sample of participants who were available and contactable. Thus the majority were accessed via three charities within a large county in the UK. Although ethnicity and social class are not considered relevant per se within a grounded theory study (Glaser 1978), all participants were white and most appeared to come from middle class backgrounds. It may be that the experience of 'living with Asperger's syndrome' and how others respond differs across different social classes and other cultures. This constitutes an important and interesting area for further study. Furthermore, the sample represents only those who had a diagnosis of Asperger's syndrome, and although increasing numbers of children are being diagnosed, at the time of data collection (2000-2001), diagnosis in the adult population was, and still is, relatively rare. Thus participants may only have received their diagnosis by virtue of the severe difficulties they were experiencing, for example, anxiety, depression, or displaying obsessive behaviour. The sample may therefore represent the less 'successful' proportion of a wider population of people 'living with Asperger's syndrome'. Whilst it is obviously more difficult to access those integrating into society more successfully (who do not have a diagnosis or acknowledge they may have Asperger's syndrome) this would be a highly interesting group of people to study. As the broader population of children who are currently being diagnosed (Baird et al 2006) grow into adulthood, greater opportunities may arise for inclusion of those who demonstrate positive coping attributes and 'symptoms of wellness' (Antonovsky 1996).

9.4 Implications for community health care practice

There are growing numbers of children being diagnosed with autism spectrum disorders, including Asperger's syndrome (Baird et al 2006), and whilst the specific genetic aetiology remains largely unknown, it is increasingly evident that genetic factors play an important role in its causation. However, it is generally believed to be a complex association between several genes, some of which remain unidentified, and does not appear to be caused by a single gene (Bailey et al 1995; Medical Research Council 2002). Nevertheless, recent advances implicating the interaction of a number of genes (Gupta and State 2007) brings the possibility of future biological markers for diagnostic testing, new types of treatment, and perhaps possibilities for the prevention of what is currently perceived as a lifelong challenging condition.

Thus as research into the biological aspects of autism spectrum disorders progresses, health care practitioners will increasingly encounter individuals and families who are living with Asperger's syndrome. However, for the moment at least, such families are living with a 'known' or 'unknown diagnosis' throughout their life course, and therefore health care practitioners, particularly working in community health care settings, need to be aware of their needs. It is therefore suggested that attention be given to how to identify people with less obvious Asperger's syndrome, how to communicate with them, and how to incorporate their perspectives, as well as their families' perspectives, into professional practice. For example, a key aspect of health visiting, described by Cowley (1991), is one of 'conveying a vision of what might be possible' for people in terms of health and well-being. This could be applied to people 'living with Asperger's syndrome', and to community health care practitioners who may encounter such people. It is hoped

that this thesis may contribute towards the understanding of people with Asperger's syndrome and their families and encourage what might be possible for achieving greater health and potential for living, even if this means a move towards "*successful different*" as opposed to the pressures and stresses of always trying to move people towards a position of fitting into society.

The challenge for community health care professionals arising from the study is to adopt an approach to understanding and supporting those living with Asperger's syndrome in the most appropriate ways. In this sense 'supporting' involves listening, understanding, and facilitating people to 'move on' towards greater health and well-being, whilst also working towards helping others to regard their fundamental differences as strengths to be valued, developed and nurtured, and furthermore, to recognise as Asperger (1944:89) himself did, that "*autistic people have their place in the organism of the social community*".

The current study identified a number of acknowledged and unacknowledged needs for individuals with Asperger's syndrome and their parents. The discovery of unidentified need is a fundamental principle of health visiting practice and education (CETHV 1977) and in this way 'fits' my own area of clinical practice. In considering the lives of 'adults' with Asperger's syndrome it is hoped that the findings from this study will inform health visitors to look beyond the scope of traditional patterns of health visiting families with young children and consider the possible hidden needs of other populations, such as adults with Asperger's syndrome, who themselves may be parents. In addition, it is anticipated that this study could help health visitors and other practitioners, including teachers, understand the 'potential' impact on children (and parents) with whom they are

currently working if their needs are not recognised, or acknowledged, during the early years of life. The aim of health care and educational endeavours with children and adults with Asperger's syndrome could be one of helping them to accept and be comfortable with their 'self', as reflected in the words of Willey (1999:17), "*though it has taken me thirty-eight years, I cannot express what a relief I feel to finally 'get' me!*"

However, as pointed out by Bryar and Bannigan (2003) changing or developing practice presents a challenge to practitioners. Thus in terms of asking health professionals and others to be more aware of the possible signs of Asperger's syndrome and recognising the challenges families may be facing, will perhaps present an even greater challenge to them than the more obvious and definitive areas of need.

9.5 Recommendations for policy and practice

Given that few policies or guidelines pertaining to the provision of care and support for people with Autism or Asperger's syndrome exist (Morton-Cooper 2004), a key recommendation is that policies be developed, both locally and nationally, that reflect the particular needs of this group of people. In doing this, it is further suggested that attention focuses on how to engage people with Asperger's syndrome and their informal carers (often parents), as well as how to incorporate their perspectives into professional practice. Such policies should recognise the life-long nature of Asperger's syndrome, and acknowledge the *not quite fitting in* phenomenon of living with Asperger's syndrome. Thus people with Asperger's syndrome have non-obvious but fundamental psychosocial needs that impinge on

their ability to fit in socially, reduce their personal and social resources for living, and affect their potential for health and fulfilment throughout their lives. In relation to the phenomenon of *not quite fitting in* and the hypotheses arising from the analysis of the study findings, a number of recommendations for policy and practice are outlined below.

9.5.1 Early detection and interventions

Early detection and interventions could make an important difference to the life chances of children with Asperger's syndrome. This thesis contends that this is important because helping children to engage more meaningfully during early socialisation processes, for example social role-play, is fundamental in gaining an understanding of the self, others, and the social world around us. It is through these processes that children learn skills of reciprocity, co-operation, and to begin to see oneself from the stance of the other. Through childhood play we begin to understand the roles and perspectives of others, which is the precursor to developing empathy, social awareness, and for a sense of belonging, or 'fitting in'.

9.5.2 Autism specific training

It is recommended that training specific to autism spectrum disorders be incorporated into the core training programmes for practitioners working with children, in particular, health visitors, school nurses, speech therapists, nursery nurses and teachers, as well as the provision of ongoing training for existing practitioners. Training is required to improve awareness of practitioners in both health care and education settings, of the early signs of autism spectrum disorders, to understand the processes involved in early childhood development and the

importance of early social play. It is also important to equip practitioners with the skills needed to facilitate environments that enable inclusion and learning for such children in order to help them integrate into the social environments of pre-school and school, reduce anxiety levels and to find ways of helping them to learn about, and engage meaningfully in early social play and 'symbolic' social interaction.

9.5.3 Assessing 'difficult' behaviours

It is recommended that practitioners who encounter people with possible Asperger's syndrome continually assess what lies behind the difficult behaviours displayed, or the 'miscommunication of gestures', and look for individual ways of reducing stress and anxiety. Children with Asperger's syndrome have to take on a considerable amount of additional 'social learning' that appears to be something that does not come naturally to them. Thus it is recommended that practitioners are made aware of the added stress that undeveloped social learning places on children with Asperger's syndrome and that this is likely to manifest as a range of challenging behaviours. A variety of strategies for reducing anxiety and calming disruptive behaviour can often be developed to help a child with Asperger's syndrome, for example, providing a highly structured environment with clear rules and routines, forewarning of changes in routine, planning ahead and preparing the child for difficult situations, limiting the amount of unstructured socialising and providing a means of 'escape' when stress levels very high.

9.5.4 Aiding communication and social interaction

When working with children and young adults with Asperger's syndrome, practitioners can aid the interaction and experience of the person with Asperger's syndrome by taking into account their subtle communication and cognitive

differences. The greater sense of 'I' over 'me and you' self in people with Asperger's syndrome can lead them to appear rude, arrogant, selfish and unfeeling towards others. They may also appear to react out of proportion to new situations, for example, by being overly anxious, angry or aggressive. Practitioners who are alert to this are less likely to take offence themselves and are more likely to take steps to understanding the cause of the behaviour and alleviate the person's fears. In aiding communication and social interaction it is advised that practitioners including teachers keep instructions short and simple to ensure they are understood and are not overloading the person with Asperger's syndrome. Also, to be as specific as possible, for example, 'Tell me how your arm got hurt?' rather than 'What happened?' and be mindful that people with Asperger's syndrome often take longer to process information and may need a longer pause before expecting an answer. Even basic rules or procedures may need to be explained and it may be useful to model what will be done, as well as what behaviour is expected of the child or young adult in that situation. It is often helpful to try to reduce distractions such as noises, lights, and smells that may be disturbing, painful or distracting. Finally, practitioners should remember that people with Asperger's syndrome will invariably have greater difficulty in understanding what is meant, and therefore to try to make allowances for this.

9.5.5 Provision of ongoing services

It is recommended that children and young people's services recognise and provide for the ongoing needs of young people with Asperger's syndrome before they reach adulthood and continuing into adulthood. The aim is to prevent many of the problems and issues that can arise for young adults and parents as reported in the study. For example, many parents argued for recognition of the socially vulnerable

position of their son or daughter, and for specialised help to help move the young person on towards greater independence and improved mental health care in terms of reducing anxieties, obsessions, sense of self worth and general well-being and happiness. For example, it is known that times of transition and change are especially difficult i.e. starting nursery, primary school, secondary school, college, employment and leaving home, thus additional provision to plan and prepare for transitions well in advance would alleviate and even ameliorate many of the issues that arise for children and their families around these times.

9.5.6 Acknowledging the impact of Asperger's syndrome on families

Practitioners can support parents by acknowledging the impact upon families of living with a child or young adult with Asperger's syndrome, and by including them in the planning and delivery of care interventions. As the current study reflects, there can be a wide range of costs for parents who are living with a son or daughter with Asperger's syndrome. For example, it can affect their own sense of emotional and social well-being and generate feelings of guilt and self-blame, as well as being blamed by others as the cause of their son or daughter's difficulties. For example, being seen or accused of being a poor parent (either too strict or not enough boundaries) or an 'overprotective' parent. As reported in the findings, parents referred to their own increasing 'social isolation' in that over the years their own social networks had diminished as a result of their son or daughter's social difficulties. Many parents felt unable to 'move on' and fulfil dreams and aspirations whilst still having a son or daughter with Asperger's syndrome living at home well into adulthood and continuing to be dependent on them emotionally, socially and practically. Many parents wanted practitioners to recognise their son or daughter's needs, but they also wanted acknowledgment of their own roles (in

their son or daughter's life), and to be listened to and included in plans for support or therapeutic interventions. It is therefore argued that help for young adults to 'move on' emotionally, socially and practically would also allow their parents to 'move on' likewise. These recommendations are intended to develop the skills and expertise of health, social care and education practitioners in identifying and supporting the needs of people during their life course, who '*do not quite fit in*'. As research into the bio-medical dimensions of autism spectrum disorder advances then it is possible that the recommendations cited in this thesis will require a modicum of amendment. However, at this moment in time, there remains a clear need for practitioners and others concerned with the welfare of young children to be knowledgeable, skilled and vigilant in supporting people with Asperger's syndrome and their families.

9.6 Suggestions for further research

With regard to the focus of future research, a potentially useful way forward could be to apply a health development paradigm (Antonovsky 1996), to examine ways of strengthening a 'sense of coherence' (comprehensibility, manageability, and meaningfulness) in people with Asperger's syndrome and their families. The aim being to build a resource for coping, to protect against potential stressors and from mental illness, and thus help people to move towards what is described as better health for the 'foundation for achievement' (Seedhouse 1986).

In addition, researchers may wish to consider addressing a number of areas for further study, including,

- longitudinal research into early interventions aiding the processes of childhood socialisation and later outcomes
- enquiries into potential costs *and* benefits of being given a diagnosis of 'Asperger's syndrome'
- research comparing different social and cultural experiences of 'living with Asperger's syndrome'
- research into the experiences and needs of families where a parent has Asperger's syndrome
- as mentioned previously, relative to the health development paradigm, to consider the positive coping attributes and 'symptoms of wellness' (Antonovsky 1996) to help others develop personal and social resources for 'living with Asperger's syndrome'

9.7 Concluding remarks

It is hoped that, in the words of Antonovsky (1996) this study together with the wider body of knowledge and continued research might “*contribute towards preventing damage, adding strength, and creating openings*” (p14) for the advancement of persons with Asperger's syndrome, their parents, families, communities and society. Whether Asperger's syndrome is a distinct disability, a different cognitive style or no more than an exaggeration of traits that can be found in all of us, what should be emphasised is that society is infinitely the poorer if such people are unable to flourish and to become *successful different*, as suggested by one parent participant. As Asperger (1944) identified sixty years ago, their personality traits and 'autistic intelligence' can actually be evolutionally adaptive. The thesis concludes by returning to the genesis of the study, that targeting appropriate help and support for people with Asperger's syndrome can only be achieved by trying to gain some insight into what it is like for them to live with Asperger's syndrome as seen through their eyes.

Appendices

Appendix 1a: Interview transcript I

Document: Parent interview: Carol [Interview 3]

Description: Uncoded interview transcript

Interview with Carol

Date of interview ...

Venue: Participant's home

Carol, I'm interested in your experiences as a parent of a young adult with Asperger's syndrome ... but the interview is a bit of an open book for you talk about the issues that are important to you and your family?

Right ... umm ... so what the impact of having somebody ... an adult son with Asperger's syndrome... a dependent adult? Well I think my first reaction is that it is sad for him ...umm I mean as a Mum ... I think empty nest syndrome is always a problem as your children grow older they go away and lead their own lives and so that the mother and perhaps the father to a lesser extent is sad then ... I don't have an empty nest ... I still have Carl very much in the nest and for me personally it's not sad because I love to have him still as part of the family but that is a very selfish response ... I know and I'd much rather for him that he was off and doing the ... you know ... the motorbike thing or having his own family and that sort of thing as far as I am concerned ... so it is sad because I suppose it is not natural that if you think of it in a biological way that the whole point of having children is for them to grow up and be independent and have their own family ... and you know to do the family thing for themselves ... so it's against nature in that way ... but mainly it's ... he sees his friends and ... umm ... for example ... we're just about to go to a family wedding in Spain ... one of his cousins is getting married and he is the only one now out of the four children in the family all in their twenties ... he's the only one who isn't married and may not be getting married ... so that's sad as well and he is aware of that and I think although he's happy at home ... we all get on very well there are no tensions ... we are all very happy ... I think he's very much aware that that's what he should be doing ... whether he actually wants to do it I don't know ... I don't know whether he's affected ... he thinks it's what he should be doing or whether it's actually what he wants to be doing so there is a bit of a gap in my knowledge umm and err that's the difficulty really that he's very much aware I think people with Asperger's are aware that they are different but they don't know what to do to address it they don't know how to make things better.

I try to help ... to do what I can to help him to be more social to have a better social life and preferably become more independent of me and the family ... partly for us because ... umm ... again it's this sort of the biological thing once your children have grown up and gone away then ... so my daughter who has done a degree in psychology tells me ... mum and dad are meant to find themselves again [smiling] to ... you know ... then go on to another phase of your marriage if you like ... and in fact we haven't got onto that phase ... I mean we are happily married there is no problem there but there but there is ... I am told ... that next step that you are meant to take and you know start enjoying yourself on a different level and we don't do that ... we are still very much the three ... the caring for somebody within the family but we are not as badly off as lots of people ... umm ...there is somebody that we know very well who is still very much more looking after his son ... you know who I'm talking about ... and we are not looking after Carl in that sense ... he's a fairly able young man and we are very lucky in that ... and I don't think he's unhappy you know ... you look around and lots of young people have stresses and strains in their life and I don't know that he's particularly more unhappy than other young people are ... but there is this big area of contact with other young people that are getting married that is a problem for him

You said your not looking after him in perhaps the way people may be looking after their dependent adult children, can you tell me a little more ... what ways do you look after Carl?

Well any financial decisions ... he wouldn't be able to make those ... I mean in terms of paying tax ... umm ... what ways? Requests for holidays at work ... I always prompt him to get the holiday form and... well really everyday processes ... there seems to be a problem at work at the moment to do with the canteen facilities everything seemed to be going OK as far as Carl having a meal at work was concerned and then for some reason they've changed the canteen facilities over ... and I know every day he just has sausage

and chips for dinner and I can't quite get to the bottom of why that is ... it could be that they've changed the menus and he doesn't like anything else that's on the menu ... but I think there might be some sort of problem in making choices and I can't quite link up with [name of supermarket employer] sufficiently well to find out if there is a problem ... so you know you are always second guessing situations ... so looking after him in that sense ... and I mean holidays he comes away ... he wouldn't go on holiday on his own ... he comes with us ... so we make all those arrangements ... basically he gets up cooks his breakfast ... he does that himself ... I've tried to make him as inde ... you know ... give him an understanding of cookery ... he does that ... goes to work on his own ... so his gets the bus fare ... train fare ... does all the stuff at [supermarket] ... comes home ... but everything else we make the decisions for really ... so that's where the looking after comes in ...

I'm interested in the 'second guessing' looking after aspect ... the fact that you have picked up on his eating sausage and chips every lunchtime because I'm sure you don't ask your daughter what she has for lunch every day?

No it's true ... yes well I do ... I do ask him what he had for lunch because that is part of our ritual ... he likes rituals and so I ask him ... I say ... 'Have a good day at work? What did you have for lunch?' ... and ... 'Did you see anybody we know?' ... those are the three standard questions ... so that's where I picked up that he had sausage and chips every day [laughs] but I suppose I wouldn't be concerned if Amy was having sausage and chips every day ... I would just assume that she had made that choice ... but for Carl I look for is there a difficulty because I know he does like to do the same things but not necessarily as regular as that ... the desserts vary I just can't work out why the main course is the same. I'll tell you another thing about the second-guessing that's quite important ... because ... for whatever reason ... Carl relates to young children and I think lots of people with Asperger's do ... partly because their not judgemental up to the age of ten or so ... and he likes kids and feels at ease with them ... and we've got a nephew in the family a little chap he's only about three and Carl loves him and we have a photo album of him and he likes that ... so he does like kids and he likes to talk to them and Carl a six foot three young man who looks perfectly normal ... he doesn't look as though he has a handicap ... and I'm always concerned about him talking to young children for obvious reasons because society isn't tolerant of that and we were away at the weekend ... we stayed in a hotel and there was a disco on in the hotel and I think this is another area where Carl has difficulties because when there is music ... he likes music and he likes to bop around and stuff and he gets frustrated when we can't join in because we are never part of that ... he's never part of that ... it is always somebody else's party ... and there were children there and he was looking at the children and he was frowning and because he gets stressed by music ... again I'm not quite sure what the reason for his difficulty is but he couldn't join in ... so he was doing odd gestures and so I said 'Carl don't do that ... that boy is looking at you' and I shouldn't have said that because then he became aware this boy was looking at him ... anyway eventually midnight or half past twelve we managed to prise him away ... he didn't want to go he wanted to stay and watch ... so we went to our rooms and were chatting and Carl was really wound up by this and so I went into his room and had a little chat with him to clam him down and stuff then we said goodnight ... I went back to our room and a minute later I went out into the corridor and there was Carl ... he hadn't finished with this disco and he was out there walking up and down the Corridor ... now I went through in my mind this scenario what if I hadn't been out there ... if Carl had met up with a young lad and started chatting to him and this young lads Dad had come round the corner and seen Carl talking to his son ... you know he could have duffed him up or something or their could have been a difficult situation ... and that's an area of concern to me you know there might not be any difficulties because as you know he a gentle lad ... he doesn't look menacing ... it might be O.K. but I'm always concerned that he's going to find himself in a situation where people aren't understanding and you know ... what are you doing talking to my son? ... And we have in fact been in that situation before at another party some years ago and so I'm concerned about that ... so again that sort of ... its not really second guessing but its being cautious for him ... whereas he would just go in and wouldn't think twice about it ... I'm just walking around the hotel at night ... you know ... because his behaviour is a bit odd ... any other person would be able to talk their way out of it ... you know ... 'Is the loo around here mate?' or something like that ... but Carl wouldn't ... so there is potential for difficulty there. Another thing he likes to go to the local primary school fayre which is a worry ... even though he's harmless others might not see he like that and wonder why he goes ... I've spoken to the headteacher... I've made a point of doing that ... of going up to the school and speaking to the headmistress first so she knows him and I think that she knows that he's safe and I always ask him to go and say hello to the headteacher ... so you just have to put little safe guards in place to avoid a difficult situation ... and again if it was Amy I wouldn't bother to do that.

I think what you've been telling me Carol ... is that there is a bit of a dichotomy between Carl on the one hand being quite a normal looking every day guy and on the other hand sometimes appearing odd or strange and saying or doing things that other people wouldn't understand?

Yeah that's right ... yes ... we live in a society where we can't reconcile the two very well ... because he looks quite normal but then in difficult situations he wouldn't be streetwise enough to give people a good explanation to explain away any odd behaviour ... which most of us can do really ... because we are aware that what we are doing is odd and so we therefore explain it but he wouldn't ... people with Asperger's aren't aware I think of that

So, you are being aware for him?

Yes that's right ... that's it ... spot on. And it's behaviour in public places ... again when we've been on holiday and there have been street musicians Carl responds in a funny sort of way and makes odd gestures and movements and people do look at him and look round ... it's funny but there are ways of being odd that are acceptable ... people would think 'Oh God look at that crazy so and so going mad' and they wouldn't think twice about it but if Carl did it they would think what's going on there ... and I can't really explain that why there is that difference but it certainly exists ... and so again after the particular holiday I'm thinking about I was so stressed by the whole thing that I just felt that I needed another holiday to get over that because it was so difficult. And so ... yes ... but I am deliberately stressing the negative things because there are lots of pluses too ... he's wonderful ... I feel I'm very privileged to still have him around living with us and we do get on well and ... umm ... and as you know we do Spanish together and I try and create ... because I'm aware that he has gaps in his life where he should be off enjoying himself with other people ... you know as parents you do try and create nice things and rituals which he likes and so I just try and make events out of things I suppose ... and I'm just trying to think what I mean by that [laughs] ... well we always have our magic moment ... our tea and toast ... where we have a chat about what we've done during the day and stuff like that ... that sort of thing that he enjoys ... I try and create a structure for him in everyday life because people with Asperger's like to have structure so he knows what to expect and ... umm ... I think when we were going away this weekend he was a bit anxious because he wasn't quite sure what was happening ... umm ... we went up specifically to go to a concert but Carl didn't want to come to so that meant Carl staying in this hotel for a couple of hours why we went off to this concert ... he was quite anxious about the whole weekend so I had to say ... 'Well right ... Friday night we'll be doing this ... we'll get to the hotel at this time and then we'll be back at eleven and then we'll go for a drink' ... and so I just had to construct a timetable for the whole weekend and then he was happy ... within that he could relax and know what the next step was ... so you have to do that all the time. That's what I try and do create structure and create sameness ... we always put the Christmas tree up on a certain weekend before Christmas and all that ... I suppose lots of people do but it's very important for Carl so we try and do that.

It sounds to me like there is an awful lot of looking after going on ... although you're not there 24 hours a day physically watching over him ... but in a sense you are always psychologically watching over him

Oh yes ... it's a 24-hour commitment ... certainly ... yes definitely

You're creating things for him, opportunities, structure, putting in place safe guards for him

That's right ... yes ... you have to manage that person's life really although a lot of it is hands off rather than hands on but somebody has to set out a structure for their lives ... people with Asperger's ... and you know it is the parents whenever they are there because it is nobody else who will do it ... And you want people to be integrated into society and enjoy the mainstream activities but it does have to be managed really ... I mean I have to have links in with [employer] ... I try and do as much as I can with them but there is a limit to how much you can be involved with your sons workplace and Shaw Trust [supported employment scheme] are there to do that but I think they could do a bit more really than they do but maybe they perceive him as being fairly able and so they don't feel that have to do a lot ... but Shaw Trust as you know ... there aren't many organisations that know very much about Asperger's Syndrome ... there are people that help people with disabilities but not specifically with Asperger's that's where parents and voluntary groups have to fill in the gaps really.

As you've talked, I've thought well I'm not sure many people would do that, as a parent of a young child you expect to do everything but as time has gone on you seem to have encompassed this as a way of life?

Yes that's right it is a way of life ... I don't think of it as a chore it is just the way we live our life and ... and that's good. He's ... I mean as I mentioned earlier ... he has a sister and she's coming up for 32 and she doesn't do an awful lot ... she's got her own life and she helps where she can but she does find difficult and

... umm she has said that when we are not here she will take over making sure ... either having Carl living with her or close by or whatever ... so it is really the whole family and you can't really expect people to do it ... umm you know it's ... I don't know ... I don't know what I think about that ... whether I do expect parents to rally or whether I think that people are entitled to their own lives and don't have any obligation ... I'm not really sure. But you know ... she does some and that's as much as you can expect.

Can you tell me what you think your daughter Amy might find difficult?

Well he's quite difficult to talk to ... it's difficult to say really ... she feels she has to entertain him which she doesn't because he's quite happy just to sit around and be there ... that's what he does here he doesn't do very much ... he always needs to be prompted to do anything ... he's very happy to help me with the chores and things at the weekends and he helps to prepare the vegetables for the meal and anything that I ask him to do but he doesn't go out and generate stuff himself ... he just comes home and he sits in the chair and watches television when there is a programme on that he wants to watch and that's about it really ... he doesn't want to do much else and he didn't as a child I recall he just used to sit on the settee here and just used to rock ... I had to keep trying to get him to ... I felt he ought to be playing he ought to be doing something rather than sit and rock ... I thought this child shouldn't be doing this and ... but I think he just didn't know what to do ... he didn't know how to play maybe and he didn't know what to play with ... I don't really know that so there is still quite an element of that ... that you have to do ... you have to structure his time for him ... or he could just sit and do nothing [laughs] or sleep or whatever

I'm just wondering how much of that is O.K. ... How much it's O.K. to be content in sitting and not talking and how much it isn't O.K.? ... Would he be more unhappy not doing anything ... not going out to work ... not achieving in any way ... it seems a difficult balance?

I have always been aware that he doesn't really have measurable successes ... you know when you go to work and have a good day ... manage to persuade somebody to do something ... whatever you do... but I don't think he has that sort of success ... he might do for all I know. I mean his customers seem to be very nice to him at Christmas ... they always give him lots of tips because he's very pleasant and non confrontational. Umm so again as you know we do the Spanish ... we go to evening classes and learn Spanish together and we did the first exam which was very simple ... it was just a formality really but it was important to me that he did it and we worked very hard on that ... learning exactly what you had to do to get through the exam ... not really a measure of how good you are at Spanish but I did feel he should have a certificate because everybody else was doing the exam and I didn't want him to be the odd one out ... so he did and he beat me at Spanish he got a 100% and I got 98 ... I don't think anybody got less than about 94 [laughs] but that was something good because that was something good a tangible measure of success ... and again that's another thing that I try to do and I was talking to David about the difficulties of this weekend the incident that I've just mentioned to you about the corridor and stuff and David said he did very well just to go to Manchester and to be in the hotel room for a couple of hours on his own because it was all new and he was absolutely right and so after that conversation I said to Carl 'I think that you did really well at the weekend I'm proud of you' and he responded to that ... he was glad of the praise ... glad of the recognition because it must have been quite hard for him you know because he is quite able you do tend to have quite high expectations really and forget the difficulties that he does have ... so I'm glad that David reminded me of that. I don't know what else I've got to say really.

I think it's O.K. to be as we are ... I mean certainly ... Bob ... Carl's Dad is going to take early retirement next year he wants to do something else with his life but that's not really related to the family [laughs] at least I don't think it is ... it could be! It's because he's done the same job for getting on for 30 years I suppose or worked for the same company and he wants to do something different ... he's got all sorts of plans for the next 10 or 20 years and so he's moving on ... I think I wouldn't want to move ... well I wouldn't want to move ... we have thought about doing additional things like because we can't really move house ... I've thought about it ... I thought about taking a job in York a few years ago but one of the reasons that we didn't was because it would have been so traumatic to Carl ... so I think we are stuck here but we do need to build something else into our lives and we've thought about getting a place ... a weekend place or something in [seaside town]... Carl knows it quite well so we could build up a society down there as well as here ... so I suppose there is moving on in that sense, umm I think one of the things about Carl working in [supermarket] is that's there are lots of [supermarkets] ... it's like teaching ... if you can teach in Hampshire you can teach in Cheshire or wherever ... so that might enable Carl to move house ... because he'll have to go because Amy wouldn't want to live here so if he's going to be cared for or to live with Amy he's going to have to go with her so he will have to move at some stage ... we've made financial arrangements ... a will and all that stuff and that's all sorted out so we've thought about that ... but that's

about it really ... not moving on but moving sideways I suppose to additional things. Even to have an extension on the house and move him to new and better bedroom was difficult ... it took a long time and I had to be devious about that and say that the only reason we are doing it was because we wanted to redecorate his old room and in fact the main reason was because we wanted him ... his old room is small ... and I wanted him to have a room that was more his area so he it could be like his own flat within the house ... his own room but he was very resistant to that as we knew ... because many people with Asperger's syndrome are resistant to change ... but he has settled in there now ... we have redecorated the old bedroom and said he could move back any time he wants to ... if he wants to sleep in there but all his stuff is in the new room and he has settled down quite well but and I don't think he wants to go back ... but he didn't see any reason to move and it was a very small room and because he's tall we got him a very big bed and the bed took over the whole room and so it was just ridiculous really ... so now it's a much bigger room and his bed is O.K. now ... he's happy enough there ... but it is an example of something most people find easy but it was a major operational thing for us ... you do have to be devious if I want him to try anything new ... even like you know we go out a meal and its cauliflower soup ... its ... 'Have I had that before?' ... I have to say 'Yes Carl you've had it lots of times before' [laughs] and then he'll try it but if I say 'no you've never had it before' he won't try it ... so in order to get him to try new things ... I mean most things ... like Spanish I had to be devious about that as well because he limits himself ... he's his own worst enemy in terms of moving on and developing his life because he's so resistant to change and afraid I think of taking on new things that he won't do it unless he can really be persuaded or tricked into doing it. For example he goes to club every Sunday night and he had an invitation to go out to dinner with them ... I found the invitation stashed away in the letter rack there and it was a perfect opportunity ... that is the sort of thing I spend my whole life trying to get Carl invitations to things like that and then it was there and he deliberately didn't tell me about it because he knew that I would be pushing ... sometimes it pays off ... at least if he tries things and then says I don't like it then well fine but 50% of the time he'll try it and will do it so I think it is right to keep on trying to present him with more opportunities

Then as a family there is the risk that we become isolated as Carl limiting his opportunities socially also limits us ... also because we are three and when we go out anywhere there are three of us and if people have a party or a gathering they feel obliged to invite Carl and that is difficult because he is quite difficult socially and certainly our neighbours over there ... they used to have ... they do have a Christmas party every year and they have young people ... sons and daughters of similar ages to Carl and it just doesn't work when their children's friends are there and Carl is there ... Carl will latch onto the young people and his conversation is odd he just doesn't fit in with them he can't join in so its embarrassing ... and because of that over the years you just get fewer and fewer invitations because people just can't cope with it and its not really fair ... its not because people aren't nice its because it is a very difficult social situation and so we go out less than we would normally ... lots of our social things are things that Carl can come and do and so you do become more isolated. We do have a few friends that over the years have known us well but it is less than we would have had ... in the past he would sometimes upset the neighbours and only stoic friends put up with us ... we became more and more isolated ... it's still isolating ... I still don't like leaving him ... people forget parents become isolated too"

I would like to do more socially because I'm a very sociable person but ... I mustn't complain because I've got lots of plusses as well as that minus so it's limiting but again my lot is not as bad as Carl's is ... so again you can't feel bad about that. But lots of people I know ... they do not make that decision ... they leave their son or daughter and I'm not blaming them for that ... that's how they want to do it and I don't know that makes the person with Asperger's unhappy ... Carl doesn't mind when we go out he says you go out that's alright ... but I feel guilty ... that's another thing you feel guilty going out and having a good time and you know your son is at home on his own so there's that aspect as well ... it's not often Bob and I go out but even when you do go out you think 'Oh gosh' ... so it's you know pluses and minuses ... but I think some people ... there is one family I know don't let it get in their way at all socially and I think that's bad really when they don't make any concessions because I think as a family there is not much support out there for people with Asperger's so if you can't be supportive within the family then their isn't much for them and they have a pretty miserable life ... so I think it is for families to be supportive ... sounds a bit judgemental initially but there you go.

Could we briefly touch on the issue of the value of a diagnosis and I know that in your situation Carl doesn't have a clinical diagnosis?

As you say we've never had a formal diagnosis and he does seem to fit all the characteristics ... I mean for me its knowing what the difficulty was of enormous value because you've got a pattern to fit things into and over the years I've gone to lots of talks and presentations about Asperger's syndrome and people talk about

Appendix 1b: Interview transcript II

Document: Young adult interview: Ben [Interview 8]

Description: NVivo document text showing paragraph numbers

Document Text:

1: Interview with Ben

2: Aged 27

3: Date of interview

4: Venue: Charity office

5:

6: Ben ... can you talk me through life story from your earliest memories through to your experiences in adulthood?

7:

8: I lived in California from about the ages of one to seven my first memories are of our house in the suburbs of San Diego ... I can't remember I think I was about four or five or so ... my memory of when I was quite young is not good I can remember like the garden, my house

9:

10:

11: Do you remember the school?

12:

13: The school ... vaguely it was about 30 miles away ... I think it was a pre-school I was about five or six ... this is really quite vague I really can't remember it is just sort of general

14:

15:

16: Tell me about the memories that are clearer

17:

18: Clear was when at the age of seven ... 1979 ... my dad moved to a place just outside Boston in New England he got a position with [Company name] computers and I went a catholic school there ... I was quite good friends with this guy ... well my family became quite good friends with his family they lived just down the road ... a guy about six months older than me called Stewart we used to spend quite a bit of time together you know just messing around ... umm life at school ... I remember I was like academically I think I was quite good at maths and science but I remember I found straight away the social ... I was aware that socially I was finding it a bit awkward you know ... I just didn't know how to fit in ... you know I didn't really make many friends but I ... umm ... [long pause, struggling to talk] this guy I was friends with was quite ... umm ... I mean I still keep in contact with him now although I haven't spoken for about four or five years ... but he was a really screwed up ... dominant aggressive type and I remember I was always timid, passive and the relationship we had was he was the boss and would say what we would do and stuff ... I remember feeling quite ... I just felt uncomfortable around people straight away I realised I was not right ... it was just a sort of vague uncomfortable feeling

19:

20: It's funny when you ask me to think about it I can't really think, it's just a jumble of memories I can't really put them together in a coherent way

21:

22:

23: You're doing really well Ben ... most of us have early memories like that. Why don't you tell me more?

24:

25: When I was about eleven my Dad moved around a lot ... umm ... I moved to Scotland a place called [...] they opened a new [...] plant up there in 1983 ... I went to a state school there and it was just much the same thing ... I felt I was different ... like I was an American and foreign and this made it really difficult. I made friends with a guy next door ... the relationship was quite similar to the one I had earlier on ... he was older than me more confident ... we used to get on quite well but at school ... I mean I liked the academic side of it I just felt really awkward ... I felt the place was quite intimidating you know ... I was quite timid ... sensitive ... I was picked on a little bit ... I wasn't the type of person who would fight back so it wasn't like ... I never got hit or anything ... it was just like verbal umm [another long pause] umm ...

26:

27:

the condition and what the limitations are and what you can and can't expect from that person ... for me that's been quite helpful as it gives me a better understanding of Carl and I know where his difficulties are and you know what he can do ... so its been useful to me and I think its been useful to us as a family ... I think certainly it is useful to have a diagnosis because in theory it should open doors for you that this provision this medical provision is for people who have Asperger syndrome ... so if you can say you've got this diagnosis then that service is open to you ... in theory I know that is a hypothetical situation because there is not a lot ... not that much there yet but it should open doors ... but again on the other hand professionals are reluctant aren't they to label people because its a syndrome and because its not clear cut and because people are different ... I think it is a very difficult diagnosis to make for anybody so I can understand where professionals are coming from when they say that ... but certainly as a parent is useful to have some indications as to what the condition is about. Umm ... I've found it difficult to discuss this with him because on the one hand I want him to understand what his difficulties are and to understand that it's O.K. to have those difficulties because it's being addressed and lots of other people have these difficulties. But I don't want him to feel too disabled, or not too different. I don't want him to feel he's an oddity because I'm trying to make him part of society and I'm trying to say its O.K. to be like this and you know everybody is different ... so it's a bit of a conflict really and I'm not sure how much he understands about Asperger's ... its not something he likes to dwell on when I do talk to him about it he doesn't want to go on about it and he doesn't like to talk about difficulties he's had in too much detail he says that's too embarrassing for me to talk about it now ... umm also on a slightly different slant he doesn't like it when people say nice things about him ... say about his work at work ... he doesn't like to dwell on that he says he finds that embarrassing so he's quite difficult to get through to in many areas and as I say I always try to talk to him about it in a positive way ... you know this is he has difficulties but that's fine ... it's O.K. to have that difficulty and we tackle it this way ... but it is quite hard to be positive about Asperger Syndrome because there aren't many pluses you know there are lots of difficulties associated with Asperger's ... not reading the rules of society and all that stuff ... its quite difficult really ... you cope in spite of it not because of it ... it's always people cope with the condition.

I think that is quite a lot ...isn't it... there is actually a huge impact on parents ... for us its not all negative ... but we have learnt to encompass the difficulties into family life and try not to let it get us down ... that's the best we can do for Carl and for ourselves.

28: How long did you stay in full time education?

29:

30: Until I was 20. I went to university in Scotland. When I got to about my fourth grade ... 16 ... I formed a friendship with these guys who were really interested in the sciences ... there were three of us and basically would just talk facts ... we didn't really take part in the social part of the school we would just sit and chat away about science and physics and I was good friends with them that was for about a year but they went to university at 16 and I stayed on an extra year for SYS studies. I tried that year about 16, 17 ... I tried to make more effort socially but it didn't really work my skills my social skills were really quite behind and I wasn't very successful. I tended to spend quite a lot of time on my own ... we actually had a ... we lived out in a house in a suburb which was just on a beach ... about 50 yards from the beach and I could actually go out onto the beach and when the tide used to go all the way out I used to spend quite a lot of time just walking around ... practice golf ... practice just dropping the ball cos it was a good mile ... the beach.

31:

32: Let me see I did ... I mean academically I did quite well ... O grades ... highers ... I did pretty well ... I got an unconditional offer at [name of Scottish university] and I studied physics and chemistry. Straight away when I'd just turned eighteen I immediately started in fresher's week ... like there is a whole social thing in drink I was really, really awkward but I immediately found that when I drank it seemed to make things a lot easier. So I started I was there three years and gradually over a second year I found a group of people who were very heavy drinkers and I found that having a relationship was based pretty much on going out ... it wasn't so bad that my socially skills were not good because we were just going out to drink ... umm ... I lost all ... I started getting pretty depressed ... so I lost all interest in my subjects umm and I kept having to drink from about then ... from the age of eighteen to now ... it has just basically been ... I mean I don't really know if there's any point in going into detail it's just been one big mess because of the alcohol ... umm ... I found that after a while I couldn't function without it and it was the only thing I look forward to ... umm ... and I spent three years at [name of university] getting progressively worse ... but because I was OK academically I could actually re-sit exams and just scrape into the next year ... but essentially I just lost all interest in it. My parents had moved down to southern England ... at that time when I was about 20 I tried another attempt at [name of university] to study chemistry again but it just went pear shaped as soon as I got to the environment ... I was drinking heavily again ... I was always very very nervous going into lectures and labs ... I remember physically throwing up and stuff because ... you know ... because of the stress. The only time I didn't feel stressed was when I was going out at night ... you know ... and just drinking heavily ... but the thing was in [new university] there wasn't that same environment ... heavy drinkers, whereas in Scotland I fitted in ... in England at [name of English university] I didn't ... I was unusual ... so I didn't even have that ... guys to go out and drink ... so I became really [emphasises really] isolated ... umm ... and I just sat and drank on my own in my room ... then one odd thing happened ... I was diagnosed as having severe depression when I left the middle of the first year. I was put on Prozac and that basically transformed me in about three weeks I found that socially I became immediately a lot more confident ... you know ... I was going out with guys and I was feeling pretty much normal and it was really good ... umm ... and I did pretty well that year ... I pretty much felt a lot better and I could study my concentration improved and I found I started you know I could actually talk to people and could actually ... well I never actually had a girlfriend but I was getting interest from girls all of a sudden and I'd actually come out of myself and people thought it was very very strange ... but unfortunately looking back the thing was that alcohol had become so much a part of my life that although I perhaps didn't need it so much I was still drinking very very heavily and eventually I don't know but I was told it would have effected how the Prozac worked and ... umm ... I certainly became depressed again and the next year I dropped out.

33:

34: I worked for a year as a trainee scientist at a company in [name of town] but again it was just not what I really wanted to do it was just something that my parents wanted ... my ex-girlfriend helped me ... she thought maybe I just needed to get into work ... it was exactly the same thing as at the university ... the work environment was stressful ... I found it socially really awkward ... I started to miss days because I felt really hung over or just too nervous to go in eventually I dropped out ... just basically not very ... you see I didn't know ... I knew something was wrong ... apart from like people were saying you're just addicted to alcohol or you're just an alcoholic ... I knew there was something else wrong but when I was diagnosed with Asperger's I was really happy because I knew ... I basically said look there is a legitimate reason ... without going into details ... it doesn't really ... I've done this quite a lot because I've had to talk to psychiatrists you know ... relate my life story

to people ... and I've also had to do it when I was diagnosed and what I'm trying to do now ... my brain just shuts down

35:

36:

37: You're going great Ben, would you like to stop for a while?

38:

39: All I can say to try to summarise ... from as soon as I can remember I was ostracised emotionally ... I felt quite intimidated ... I was victimised ... maybe not physically but people could see I was nervous and timid and would take advantage. Friends ... you know people who were more sensitive ... I would get on with them but the relationship was always one sided they were the boss ... close friends I've had and I was quite submissive ... umm ... as soon as I started drinking heavily about the age of eighteen, nineteen basically the only people when out socially I felt calmest was when I was under the influence of alcohol ... that just removed all the fear and anxiety and you know I paid the price when you drink heavily ... with health problems and the depression or have you ... and let's see ... oh yeah ... two or three suicide attempts over the years ... the first time I was about twenty three that's when I had to drop university the first time ... I saw this as a way out of the life I have ... it's the ultimate opt out isn't it?

40:

41: When I was diagnosed with Asperger's Syndrome I felt quite a bit better but I was admitted the first time into hospital in April 1988 with severe depression, they thought I was a suicide risk as I had previously attempted and I had been drinking really heavily and got into trouble and I was in hospital two and a half months err between April and June I was diagnosed with Asperger's when I was actually in [name of psychiatric hospital]

42:

43:

44: It was at [name of psychiatric hospital] that you were diagnosed?

45:

46: Oh no no it wasn't ... they were sceptical of the whole thing ... I read a book ... the book you've got up there 'Asperger Syndrome' and I thought ... yeah that's all pretty plausible ... umm ... my mother actually saw a programme on it ... and it was just another thing well maybe you've got Asperger's and I was just 'yeah, yeah' but when I read it I thought yes this does look actually what I've got ... and they were sceptical at the hospital and the psychiatrists were saying oh well if we gave you a book on schizophrenia would you think you had it? I said 'No' ... they said oh you've got social phobia ... which I don't think I have ... a phobia is an irrational fear ... that's what I tried to explain ... phobia's are irrational ... I had a rational fear of being rejected because I always was ... umm as a kid ... and so I wasn't diagnosed there ... my mother arranged for me to see Lorna Wing in London ... they gave me a test an IQ test when I was there and I scored quite high on the verbal ... verbal is like 133 and perceptual side was 108 and it worked out I guess it was weighted for the verbal I get about 126 or something ... but they were saying that that was very unusual ... the difference in the two sides but was the reason why I had actually compensated so well ... and why it was difficult to tell ... it took so long to find out because I compensated ... I could actually intellectually compensate for it ... umm ... the reason I guess why I got involved with booze was that the social to relieve the social anxiety ... umm ...

47:

48: I don't know it's just pretty uneventful. A lot of well university failing ... jobs or what have you ... lost friends ... I don't know if it's because I've got Asperger's or because I drink heavily or a bit of both but I was told ... Lorna Wing said this ... oh yeah ... that socially I'm actually quite good and people cannot tell ... but the thing is I'm still very nervous and I'm still scared of being ostracised ... The problem is now and this is the common theme that runs from the age of eighteen, nineteen, is like the problem was Asperger's initially, but the problem with alcohol became the primary thing and it is now ... I'm not sure exactly ... the story is pretty pessimistic ... I did try lots of times to get help a lot of the time I don't really feel it's worked but you know the isolation ... this stuff always seems to come back and I don't know if that's because of the booze because I do become quite solitary when I'm drinking and become quite antisocial ... I'm not really a nice person to be around as far as that goes

49:

50: I've talked to a guy who has mild Asperger's this guy, Steve, who had similar problems ... he got into drugs and stuff he almost got put in prison he smashed up a hostel where he lived. It seems par for the course that people with the high functioning the high end of Asperger's ... all I can reason is if people have it severely they don't realise there is a problem ... they are blissfully

unaware but for us you realise there is something quite wrong ... something terribly wrong that you can't really put your finger on it you know and it's the awareness that's the killer I think ... I guess that's what causes the depression and self loathing, drugs, alcohol ... umm ...

51:

52: If we're talking about my life story I just don't feel it's really worth ... I mean it's not all doom and gloom I have accomplished ... I worked in a very challenging environment for a year in a pharmaceutical company ... I was told I learned really well ... I have actually done well I was competent and they wouldn't let me do the job I wanted ... it was one of the lowest positions in the company ... they had a special room where they autoclaved to sterilise and a special washing up technique in the preparation of glassware and I said 'this is what I want to do ... I like this job' ... they said 'No, we're afraid we won't give it to you ... you're too' ... basically saying you should be working in research and development ... I couldn't make it clear to them I didn't want that stress ... I wanted something that had a similar structure everyday and I really did enjoy it and I was on my own a lot of the time and I didn't get it ... soon after that I basically had a few times when I missed work and I just packed it in one day ... I said I can't take it so just resigned. So basically you know I have the ability but I guess whatever causes it the anxiety, lack of self-confidence is basically wrecking everything ... so there we are.

53:

54:

55:

56: Thank you Ben ... I think we're almost finished ... could you just tell me what your hopes for the future are?

57:

58: Um I don't know ... recently I've been thinking seriously ... I realised that basically that I have to cool it ... you know cool it drinking the thing is about the drink I'll go for two weeks without a drink and then I'll go bang and I'll just drink off a bottle of vodka everyday for five days in a row ... umm ... I'll often black out and get into trouble with the police and that keeps wrecking things ... I'm ... I keep trying to do things like working ... playing sport and I realise that I either solve how I can cope with life or accept I'm never going to have a career and never going to have a girlfriend or family ... maybe ... I just don't want it ... I just don't want any responsibility ... so I don't to have to deal with society and that would be my way of just saying I'm not interested anymore ... maybe this is my way of surviving. But right now I'm stuck in between two lives and which way I want to go. That's pretty much my life ... I don't know if you talk to adults with Asperger's I guess a lot get very depressed and I guess that's what happened to me and I didn't know what was wrong so got hooked on alcohol ... and I sometimes think that if I'd have been diagnosed when I was 19 and told that you're not just odd or antisocial there's a real problem ... in some ways I feel it's too late I'm 27 ... my life's pretty much wrecked ... now I've got to start pretty much over again ... you know I'm not sure if I want too ... umm ... that's my life story.

Appendix 1c: Document coding report

Document: Young adult interview: Ben

Description: NVivo report: line by line open coding, linked by paragraph numbers

Code 1 of 1452	depressed
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32: *I started getting pretty depressed*

Code 2 of 1452	likeminded friendships
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30: *I formed a friendship with these guys who were really interested in the sciences*

Code 3 of 1452	isolated
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32: *so I became really [emphasises really] isolated ... umm ... and I just sat and drank on my own in my room*

Code 4 of 1452	it's the awareness that's the killer
----------------	--------------------------------------

50: *it's the awareness that's the killer*

Code 5 of 1452	not fitting in
----------------	----------------

18: *just didn't know how to fit in*
32: *there wasn't that same environment ... heavy drinkers, whereas in Scotland I fitted in ... in England at [name of English university] I didn't ... I was unusual ... so I didn't even have that*

Code 6 of 1452	socially awkward
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34: *it was exactly the same thing as at the university ... the work environment was stressful ... I found it socially really awkward ... I started to miss days because I felt really hung over or just too nervous to go in eventually I dropped out*

Code 7 of 1452	feeling awkward
----------------	-----------------

18: *I remember I found straight away the social ... I was aware that socially I was finding it a bit awkward you know*
25: *just felt really awkward ...*

Code 8 of 1452	victimised
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39: *from as soon as I can remember I was ostracised emotionally ...I felt quite intimidated ... I was victimised ... maybe not physically but people could see I was nervous and timid and would take advantage*

Code 9 of 1452	ostracised emotionally
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39: *from as soon as I can remember I was ostracised emotionally ...I felt quite intimidated ... I was victimised ... maybe not physically but people could see I was nervous and timid and would take advantage*

Code 10 of 1452	quite good friends
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18: *I was quite good friends with this guy*

Code 11 of 1452	academically clever
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18: *academically I think I was quite good at maths and science*
32: *I mean academically I did quite well ... O grades ... highers ... I did pretty well ... I got an unconditional offer at [name of Scottish university] and I studied physics and chemistry.*

Code 12 of 1452	awareness of difference
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18: *I was aware*
18: *I realised I was not right*

Code 13 of 1452	didn't know how to fit in
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18: *I didn't know how to fit in*

Code 14 of 1452	didn't know how to fit in
18: <i>I didn't really make many friends</i>	
Code 15 of 1452	vague uncomfortable feeling
18: <i>it was a vague uncomfortable feeling</i>	
Code 16 of 1452	I was not right
18: <i>I was not right</i>	
Code 17 of 1452	timid, passive
18: <i>I was always timid, passive</i>	
Code 18 of 1452	unequal friendships
18: <i>the relationship we had was he was the boss and would say what we would do and stuff</i>	
Code 19 of 1452	difficulties with recall
20: <i>It's funny when you ask me to think about it I can't really think, it's just a jumble of memories I can't really put them together in a coherent way</i>	
Code 20 of 1452	feeling different
25: <i>I felt I was different</i>	
Code 21 of 1452	like academic work
25: <i>I liked the academic side of it</i>	
Code 22 of 1452	intimidated
25: <i>I felt the place was quite intimidating you know</i>	
Code 23 of 1452	made friends
25: <i>I made friends with a guy next door</i>	
Code 24 of 1452	picked on at school
25: <i>I was picked on a little bit ... I wasn't the type of person who would fight back so it wasn't like ... I never got hit or anything ... it was just like verbal</i>	
Code 25 of 1452	verbal attacks only
25: <i>I never got hit or anything ... it was just like verbal</i>	
Code 26 of 1452	went to university
30: <i>went to university in Scotland</i>	
Code 27 of 1452	couldn't defend self
25: <i>I wasn't the type of person who would fight back</i>	
Code 28 of 1452	friends: shared interests in science rather than social
30: <i>there were three of us and basically would just talk facts ... we didn't really take part in the social part of the school we would just sit and chat away about science and physics and I was good friends with them that was for about a year</i>	
Code 29 of 1452	tried to develop socially - not successful
30: <i>I tried to make more effort socially but it didn't really work my skills my social skills were really quite behind</i>	
Code 30 of 1452	underdeveloped social skills
30: <i>my skills my social skills were really quite behind</i>	
Code 31 of 1452	spent time alone
30: <i>I tended to spend quite a lot of time on my own ...we actually had a ... we lived out in a house in a suburb which was just on a beach ... about 50 yards from the beach and I could actually go out onto the beach and when the tide used to go all the way out I used to spend quite a lot of time just</i>	

walking around ... practice golf ... practice just dropping the ball cos it was a good mile ... the beach.

Code 32 of 1452 social drinking to ease social awkwardness

32: *Straight away when I'd just turned eighteen I immediately started in Fresher's week ...like there is a whole social thing in drink I was really, really awkward but I immediately found that when I drank it seemed to make things a lot easier.*

Code 33 of 1452 relations based around drinking

32: *I was there three years and gradually over a second year I found a group of people who were very heavy drinkers and I found that having a relationship was based pretty much on going out*

Code 34 of 1452 social skills didn't matter

32: *it wasn't so bad that my socially skills were not good because we were just going out to drink ...*

Code 35 of 1452 lost interest in studies

32: *so I lost all interest in my subjects umm and I kept having to drink*

Code 36 of 1452 alcohol messed life up

32: *it's just been one big mess because of the alcohol*

Code 37 of 1452 getting progressively worse

32: *getting progressively worse*

Code 38 of 1452 academically compensated

32: *but because I was OK academically I could actually re-sit exams and just scrape into the next year*

Code 39 of 1452 very nervous, sick with stress

32: *I was always very very nervous going into lectures and labs ... I remember physically throwing up and stuff because ... you know ... because of the stress.*

Code 40 of 1452 not stressed when drinking

32: *The only time I didn't feel stressed was when I was going out at night ... you know ... and just drinking heavily*

Code 41 of 1452 heavy drinking not part of new social scene

32: *there wasn't that same environment ... heavy drinkers, whereas in Scotland I fitted in ... in England at [name of English university] I didn't ...I was unusual ... so I didn't even have that ... guys to go out and drink ... so I became really [emphasises really] isolated ...*

Code 42 of 1452 gained confidence on Prozac

32: *then one odd thing happened ... I was diagnosed as having severe depression when I left the middle of the first year. I was put on Prozac and that basically transformed me in about three weeks I found that socially I became immediately a lot more confident*

Code 43 of 1452 feeling normal

32: *I was going out with guys and I was feeling pretty much normal and it was really good*

Code 44 of 1452 people noticed him

32: *I pretty much felt a lot better and I could study my concentration improved and I found I started you know I could actually talk to people and could actually ... well I never actually had a girlfriend but I was getting interest from girls all of a sudden and I'd actually come out of myself and people thought it was very very strange ...*

Code 45 of 1452 drinking continued

32: *but unfortunately looking back the thing was that alcohol had become so much a part of my life that although I perhaps didn't need it so much I was still drinking very very heavily and eventually I don't know but I was told it would have effected how the Prozac worked and ... umm ... I certainly became depressed again*

Code 46 of 1452	dropped out of university	<i>32: I certainly became depressed again and the next year I dropped out.</i>
Code 47 of 1452	trainee scientist	<i>34: I worked for a year as a trainee scientist</i>
Code 48 of 1452	not what he wanted to do	<i>34: but again it was just not what I really wanted to do it was just something that my parents wanted ... my ex-girlfriend helped me ... she thought maybe I just needed to get into work</i>
Code 49 of 1452	what others wanted	<i>34: it was just not what I really wanted to do it was just something that my parents wanted ... my ex-girlfriend helped me ... she thought maybe I just needed to get into work</i>
Code 50 of 1452	stressful work environment	<i>34: it was exactly the same thing as at the university ... the work environment was stressful</i>
Code 51 of 1452	knew something wrong	<i>34: just basically not very ... you see I didn't know ... I knew something was wrong ... apart from like people were saying you're just addicted to alcohol or you're just an alcoholic ... I knew there was something else wrong</i>
Code 52 of 1452	people believed he was alcoholic	<i>34: apart from like people were saying you're just addicted to alcohol or you're just an alcoholic</i>
Code 53 of 1452	happy when Asperger's syndrome diagnosed	<i>34: when I was diagnosed with Asperger's I was really happy because I knew ... I basically said look there is a legitimate reason</i>
Code 54 of 1452	legitimatised problems	<i>34: legitimate reason</i>
Code 55 of 1452	talked often about life story	<i>34: I've done this quite a lot because I've had to talk to psychiatrists you know ... relate my life story to people ... and I've also had to do it when I was diagnosed and what I'm trying to do now</i>
Code 56 of 1452	ostracised and intimidated	<i>39: from as soon as I can remember I was ostracised emotionally ... I felt quite intimidated ... I was victimised ... maybe not physically but people could see I was nervous and timid and would take advantage.</i>
Code 57 of 1452	brain shuts down	<i>34: my brain just shuts down</i>
Code 58 of 1452	one sided relationships	<i>39: Friends ... you know people who were more sensitive ... I would get on with them but the relationship was always one sided they were the boss ... close friends I've had and I was quite submissive</i>
Code 59 of 1452	calmest when drinking	<i>39: when out socially I felt calmest was when I was under the influence of alcohol ... that just removed all the fear and anxiety</i>
Code 60 of 1452	health costs of drinking	<i>39: I paid the price when you drink heavily ... with health problems and the depression 9</i>
Code 61 of 1452	suicide attempts	

39: two or three suicide attempts over the years ... the first time I was about twenty three that's when I had to drop university the first time ... I saw this as a way out of the life I have ... it's the ultimate opt out isn't it?

Code 62 of 1452 opting out

39: two or three suicide attempts over the years ... the first time I was about twenty three that's when I had to drop university the first time ... I saw this as a way out of the life I have ... it's the ultimate opt out isn't it?

Code 63 of 1452 felt better when diagnosed

41: When I was diagnosed with Asperger's Syndrome I felt quite a bit better

Code 64 of 1452 psychiatric hospital

41: I was admitted the first time into hospital in April 1988 with severe depression, they thought I was a suicide risk as I had previously attempted and I had been drinking really heavily and got into trouble and I was in hospital two and a half months err between April and June I was diagnosed with Asperger's when I was actually in [name of psychiatric hospital]

Code 65 of 1452 professional sceptical of Asperger's syndrome

46: Oh no no it wasn't ... they were sceptical of the whole thing ... I read a book ... the book you've got up there 'Asperger Syndrome' and I thought ... yeah that's all pretty plausible ... umm ... my mother actually saw a programme on it ... and it was just another thing well maybe you've got Asperger's and I was just 'yeah, yeah' but when I read it I thought yes this does look actually what I've got ... and they were sceptical at the hospital and the psychiatrists were saying oh well if we gave you a book on schizophrenia would you think you had it? I said 'No' ... they said oh you've got social phobia ... which I don't think I have ... a phobia is an irrational fear ... that's what I tried to explain ... phobia's are irrational ... I had a rational fear of being rejected because I always was

Code 66 of 1452 self recognition of Asperger's syndrome

46: I read a book ... the book you've got up there 'Asperger Syndrome' and I thought ... yeah that's all pretty plausible ... umm ... my mother actually saw a programme on it ... and it was just another thing well maybe you've got Asperger's and I was just 'yeah, yeah' but when I read it I thought yes this does look actually what I've got

Code 67 of 1452 mother saw programme

46: my mother actually saw a programme on it

Code 68 of 1452 rejection of social phobia diagnosis

46: they said oh you've got social phobia ... which I don't think I have ... a phobia is an irrational fear ... that's what I tried to explain ... phobia's are irrational

Code 69 of 1452 diagnosed by Lorna Wing

46: my mother arranged for me to see Lorna Wing in London ...

Code 70 of 1452 mother arranged private assessment

46: my mother arranged for me to see Lorna Wing in London ...

Code 71 of 1452 unusual IQ

46: they gave me a test an IQ test when I was there and I scored quite high on the verbal ... verbal is like 133 and perceptual side was 108 and it worked out I guess it was weighted for the verbal I get about 126 or something ... but they were saying that that was very unusual

Code 72 of 1452 intellectual compensation

46: they gave me a test an IQ test when I was there and I scored quite high on the verbal ... verbal is like 133 and perceptual side was 108 and it worked out I guess it was weighted for the verbal I get about 126 or something ... but they were saying that that was very unusual ... the difference in the two sides but was the reason why I had actually compensated so well ... and why it was difficult to tell ... it took so long to find out because I compensated ... I could actually intellectually compensate for it

Code 73 of 1452	alcohol relieved social anxiety
46: <i>the reason I guess why I got involved with booze was that the social to relieve the social anxiety</i>	
Code 74 of 1452	a lot of failing
48: <i>A lot of well university failing ... jobs or what have you ...lost friends</i>	
Code 75 of 1452	Alcohol versus Asperger's syndrome as the main problem
48: <i>The problem is now and this is the common theme that runs from the age of eighteen, nineteen, is like the problem was Asperger's initially, but the problem with alcohol became the primary thing and it is now ... I'm not sure exactly</i>	
Code 76 of 1452	the story is pretty pessimistic
48: <i>the story is pretty pessimistic</i>	
Code 77 of 1452	tried to seek help
48: <i>I did try lots of times to get help a lot of the time I don't really feel it's worked but you know the isolation ... this stuff always seems to come back</i>	
Code 78 of 1452	problems always come back
48: <i>this stuff always seems to come back</i>	
Code 79 of 1452	solitary person
48: <i>I do become quite solitary when I'm drinking and become quite antisocial</i>	
Code 80 of 1452	not nice when drinking
48: <i>I'm not really a nice person to be around as far as that goes</i>	
Code 81 of 1452	talked with man with Asperger's syndrome
50: <i>I've talked to a guy who has mild Asperger's this guy, Steve, who had similar problems</i>	
Code 82 of 1452	depression par for the course
50: <i>It seems par for the course that people with the high functioning the high end of Asperger's ... all I can reason is if people have it severely they don't realise there is a problem ... they are blissfully unaware that you can't really put your finger on it you know and it's the awareness that's the killer I think ... I guess that's what causes the depression and self loathing, drugs, alcohol ... umm ...</i>	
Code 83 of 1452	awareness causes self loathing
50: <i>I guess that's what causes the depression and self loathing, drugs, alcohol ...</i>	
Code 84 of 1452	awareness the killer
50: <i>it's the awareness that's the killer I think ... I guess that's what causes the depression and self-loathing, drugs, alcohol ... umm ...</i>	
Code 85 of 1452	something quite wrong, terribly wrong
50: <i>but for us you realise there is something quite wrong ... something terribly wrong</i>	
Code 86 of 1452	intangible
50: <i>you can't really put your finger on it you know</i>	
Code 87 of 1452	accomplishments
52: <i>not all doom and gloom I have accomplished</i>	
Code 88 of 1452	wanted 'simple job' but refused by others
52: <i>I have actually done well I was competent and they wouldn't let me do the job I wanted ... it was one of the lowest positions in the company ... they had a special room where they autoclaved to sterilise and a special washing up technique in the preparation of glassware and I said 'this is what I want to do ... I like this job' ... they said 'No, we're afraid we won't give it to you ... you're too' ...</i>	

basically saying you should be working in research and development ... I couldn't make it clear to them I didn't want that stress ... I wanted something that had a similar structure everyday and I really did enjoy it and I was on my own a lot of the time and I didn't get it

Code 89 of 1452 didn't want stress
52: *I didn't want that stress*

Code 90 of 1452 wanted routine and structure
52: *I wanted something that had a similar structure everyday and I really did enjoy it and I was on my own a lot of the time and I didn't get it*

Code 91 of 1452 resigned as couldn't cope with stress
52: *soon after that I basically had a few times when I missed work and I just packed it in one day ... I said I can't take it so just resigned.*

Code 92 of 1452 ability but lacks self belief
52: *So basically you know I have the ability but I guess whatever causes it the anxiety, lack of self-confidence*

Code 93 of 1452 anxiety wrecking everything
52: *is basically wrecking everything*

Code 94 of 1452 trying to sort self out
58: *I keep trying to do things like working ... playing sport*

Code 95 of 1452 accept limitations
58: *I keep trying to do things like working ... playing sport and I realise that I either solve how I can cope with life or accept I'm never going to have a career and never going to have a girlfriend*

Code 96 of 1452 surviving
58: *maybe this is my way of surviving.*

Code 97 of 1452 doesn't want responsibility
58: *maybe ... I just don't want it ... I just don't want any responsibility*

Code 98 of 1452 stuck between two lives
58: *But right now I'm stuck in between two lives*

Code 99 of 1452 which way to go?
58: *I'm stuck in between two lives and which way I want to go.*

Code 100 of 1452 depression
58: *I guess a lot get very depressed and I guess that's what happened to me and I didn't know what was wrong so got hooked on alcohol*

Code 101 of 1452 diagnosis too late
58: *I sometimes think that if I'd have been diagnosed when I was 19 and told that you're not just odd or antisocial there's a real problem ... in some ways I feel it's too late I'm 27*

Code 102 of 1452 life wrecked
58: *my life's pretty much wrecked*

Code 103 of 1452 too late to change
58: *in some ways I feel it's too late I'm 27... now I've got to start pretty much over again ... you know I'm not sure if I want to.*

Appendix 1d: Full coding report

<p>1. Young adult experiences</p> <p>2. <u>Appearance</u></p> <p>3. <i>non-obvious disability</i></p> <p>4. academically compensates</p> <p>5. appears intelligent</p> <p>6. appropriate dress</p> <p>7. appropriate outward</p> <p>8. attractive</p> <p>9. awareness of difference</p> <p>10. awareness of self / image</p> <p>11. carefully dressed</p> <p>12. copies others</p> <p>13. covers up</p> <p>14. dominates interaction</p> <p>15. good looking</p> <p>16. hidden disability</p> <p>17. intense attachments</p> <p>18. to animals</p> <p>19. to objects</p> <p>20. knows how to act</p> <p>21. looks normal</p> <p>22. non-disabled</p> <p>23. normal looking</p> <p>24. ordinary, regular guy</p> <p>25. pretending to be normal</p> <p>26. particular</p> <p>27. self-perception</p> <p>28. sense of others</p> <p>29. talks normally</p> <p>30. takes care over appearance</p> <p>31. reserved</p> <p>32. smart</p> <p>33. <u>Not quite fitting - appearance</u></p> <p>34. acceptable odd</p> <p>35. awkward</p> <p>36. cannot read his face</p> <p>37. different from different</p> <p>38. difficult to describe</p> <p>39. 'doesn't fit his skin'</p> <p>40. behaviour gives him away</p> <p>41. can't put your finger on it</p> <p>42. expressionless</p> <p>43. fussy</p> <p>44. gullible</p> <p>45. high anxiety</p> <p>46. ill-coordinated</p> <p>47. indescribable</p> <p>48. looks eccentric</p> <p>49. looks serious</p> <p>50. looks miserable</p> <p>51. lout</p> <p>52. mismatched looks with</p> <p>53. behaviour</p> <p>54. nervous looking</p> <p>55. never smiled as a baby</p> <p>56. not different enough</p> <p>57. not quite right</p> <p>58. not quite different</p> <p>59. not the same</p> <p>60. painfully shy</p> <p>61. partial awareness of image</p> <p>62. particular</p> <p>63. passive</p> <p>64. poor dress sense</p> <p>65. old fashioned</p> <p>66. overpowering</p> <p>67. socially awkward</p> <p>68. something strange</p>	<p>69. scruffy</p> <p>70. some sense of others</p> <p>71. 'spacey'</p> <p>72. takes over</p> <p>73. tone of voice</p> <p>74. monotonous</p> <p>75. high pitch</p> <p>76. uncomfortable eye contact</p> <p>77. looks away</p> <p>78. stares too long</p> <p>79. sticks out in a crowd</p> <p>80. uncomfortable looking</p> <p>81. Obviously odd</p> <p>82. flaps around</p> <p>83. dresses out of season</p> <p>84. eye contact</p> <p>85. little</p> <p>86. stares inappropriately</p> <p>87. geekish</p> <p>88. inappropriate dress / behaviour</p> <p>89. little sense of others</p> <p>90. no dress coordination</p> <p>91. oblivious to self appearance</p> <p>92. oblivious to how others see him</p> <p>93. obsessive</p> <p>94. poor physical coordination</p> <p>95. visibly odd</p> <p>96. unacceptable odd</p> <p>97. unaware of difference</p> <p>98. uncoordinated physically</p> <p>99. wears same clothes continually</p> <p>100. <u>Feelings</u></p> <p>101. <u>Awareness</u></p> <p>102. a lonely life</p> <p>103. levels of self-awareness/insight</p> <p>104. awareness causes self-loathing</p> <p>105. awareness of difference</p> <p>106. awareness the killer</p> <p>107. aware before diagnosis</p> <p>108. diagnosis brings explanation</p> <p>109. diagnosis brings relief</p> <p>110. diagnosis legitimises feelings</p> <p>111. don't know if he's affected</p> <p>112. feeling different</p> <p>113. feeling normal</p> <p>114. 'I was not right'</p> <p>115. intangible</p> <p>116. it's awareness that kills</p> <p>117. keep hidden v's telling</p> <p>118. not all doom and gloom</p> <p>119. accomplishments</p> <p>120. oblivious to difference</p> <p>121. of difference</p> <p>122. open awareness</p> <p>123. partial awareness</p> <p>124. perception of problems</p> <p>125. perception=pain</p> <p>126. problems always come back</p> <p>127. profound insights</p> <p>128. something quite wrong</p> <p>129. terribly wrong</p> <p>130. Sense of self/others</p> <p>131. accept limitations</p> <p>132. 'always wondering who I</p>	<p>133. am'</p> <p>134. an alien</p> <p>135. awareness of difference</p> <p>136. be in a world of his own</p> <p>137. can be no other way</p> <p>138. childhood experiences</p> <p>139. comparing with others</p> <p>140. didn't know how to fit in</p> <p>141. different need to be different</p> <p>142. proud to be different</p> <p>143. want to be different</p> <p>144. different self</p> <p>145. different soul</p> <p>146. distorted</p> <p>147. do not fit in</p> <p>148. don't want to fit in</p> <p>149. desperate to fit in</p> <p>150. failure</p> <p>151. false</p> <p>152. foreigner</p> <p>153. foreign land</p> <p>154. from a different planet</p> <p>155. genuine self</p> <p>156. individual</p> <p>157. insight</p> <p>158. intrusive</p> <p>159. knew something wrong</p> <p>160. lacks awareness of others</p> <p>161. lacks awareness of self</p> <p>162. lacks confidence in self</p> <p>163. lacks motivation</p> <p>164. lacks remorse</p> <p>165. lacks self-belief</p> <p>166. lacks sense of others</p> <p>167. longing to be accepted</p> <p>168. looking for self</p> <p>169. low self esteem</p> <p>170. low sense of self:</p> <p>171. 'I wish I knew who I was'</p> <p>172. wanting to be someone else</p> <p>173. wanting to be like others</p> <p>174. 'who am I?'</p> <p>175. never fitted in</p> <p>176. never part of that</p> <p>177. no self identity</p> <p>178. not a sheep</p> <p>179. not bound by conventional thinking</p> <p>180. not bound by others views</p> <p>181. not nice</p> <p>182. odd one out</p> <p>183. original self</p> <p>184. outside of body looking on</p> <p>185. outsider</p> <p>186. perception of self</p> <p>187. perception of difference = pain</p> <p>188. personality suicide</p> <p>189. searching for home</p> <p>190. searching for self</p> <p>191. self-absorbed</p> <p>192. self-centred</p> <p>193. self-destruct</p> <p>194. self-dislike</p> <p>195. self-doubts</p> <p>196. self-identity</p> <p>197. self-loathing</p> <p>198. self-questioning</p> <p>199. social identity</p> <p>200. social outcast</p> <p>201. solitary self</p> <p>202. superficial</p> <p>203. remorseless</p> <p>204. unrealistic</p>
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205. Emotions	278. in a mess	349. solitude
206. aggression	279. intimidated	350. substance misuse
207. ambivalent to parents	280. limits self	351. suicide attempts
208. anxiety	281. miserable	352. suicide thoughts
209. anger	282. muddled	353. survival mission
210. anxiety holds him back	283. never happy	354. taps
211. argumentative	284. not all doom and gloom	355. the story is pretty pessimistic
212. believes his own lies	285. not coping	356. timid/passive
213. life wrecked	286. rejects conformist society on the outside resigned	357. tried to develop socially
214. loneliness	287. one sided relationships	358. tried to seek help
215. morbid	288. ostracised	359. trying to sort self out unsustainable
216. negative	289. overload	360. victimised
217. nervousness	290. philosophical	361. violent temper
218. pessimistic	291. profound thinker	362. watching others
219. pessimistic life story	292. so bored	363. writes lists
220. philosophical	293. so lonely	364. Not quite fitting – behaviour
221. psychological pain	294. terrible ordeal meeting people	365. a bit odd
222. regret	295. too honest	366. acceptable odd /unacceptable
223. resentment	296. too stressed to cope	367. aggressive
224. of parents	297. too scary to cry	368. altered accent
225. of peers	298. unloved	369. always punctual
226. of others	299. unmotivated	370. amazing memory
227. of siblings	300. unreal	371. anxious to please
228. resilience	301. <u>Behaviour</u>	372. appears arrogant
229. high	302. Social survival/coping	373. attached to objects
230. low	303. alcohol/drugs	374. attaches himself to women
231. unusual quality	304. able to socialise	375. beat her up
232. sadness	305. academic focus	376. bath a real problem
233. so lonely	306. academically clever	377. behavioural problems
234. socially unaware	307. accepted	378. bizarre:
235. strange sensitivity/insensitivity	308. all an act	379. hand flapping
236. strong feelings	309. avoidance	380. strange interests
237. suicidal	310. avoiding social situations	381. cautious
238. temper	311. being different	382. childish
239. torment	312. being socially acceptable	383. can't answer door
240. uncomplaining	313. brain shuts down	384. can't judge speeds
241. unhappiness	314. calm when drinking	385. can't pick up phone
242. unfulfilled	315. collecting objects	386. can't talk way out of trouble
243. wound up	316. compensating	387. conflicts
244. Not quite fitting - feelings	317. copying	388. couldn't defend self
245. always being on my own	318. creates personae	389. curious:
246. an alien	319. dressing up	390. 'Mr Bean behaviour'
247. antisocial	320. dropped out	391. walks bent over
248. brain shuts down	321. of university	392. compensating:
249. can't cope	322. trainee scientist	393. ability hides disability
250. 'can't put your finger on it'	323. echoes others	394. academic achievements
251. can't make choices	324. fantasising	395. compulsions
252. comparing with others	325. hiding	396. crazy
253. confined	326. impersonate	397. cruel without meaning to be
254. couldn't relate to anyone	327. inflexible	398. curious
255. daydreamer	328. intellectual compensation	399. debilitate
256. deep	329. intense interests	400. defiance
257. different expectations	330. learn to play normal game	401. destructive
258. different from different	331. how to behave	402. 'didn't play like other children'
259. disconnected	332. how to look	403. different
260. distractibility	333. what to say	404. difficulties with recall
261. doesn't want responsibility	334. preoccupation	405. difficulty in socialising
262. effort	335. pretence	406. disastrous
263. emotionally ostracised	336. pretending to be normal	407. disjointed
264. escapism	337. pretending to be old	408. disobedient
265. everything a big effort	338. opposing the trend	409. disorganised
266. expectations of self	339. opting out	410. distracted
267. harsh	340. jobs	411. dominates conversation
268. unrealistic	341. life	412. one-way
269. failing	342. relationships	413. only interested in own subject
270. failure	343. society	414. talks over people
271. feeling awkward	344. ostracised emotionally	415. eccentric
272. feels unlovable	345. reserved	416. experimenting
273. frustrated	346. recluse	417. effort
274. getting progressively worse	347. reliance on parents	418. erotic fascinations
275. hopes and aspirations	348. running away	419. everyday encounters a
276. life a nightmare		
277. 'I'm in turmoil'		

420. he doesn't go out and generate stuff	489. being watched	555. problem
421. he's fairly able	490. constant checking	556. exact
422. hits people	491. 'everyone staring at me'	557. extraordinary
423. hysterical	492. patronising	558. extremely rational
424. 'I don't cooperate'	493. pedantic	559. flung food across room
425. I loved exam time	494. perfectionist	560. friendships
426. immature	495. persecuted	561. high expectations
427. impulsive	496. 'pressure-cooker'	562. one-sided
428. indifferent	497. presumptuous	563. not lasting
429. in trouble with police	498. problems in the playground	564. had to wear a hat
430. inappropriate behaviour	499. quiet	565. happy to be alone
431. inappropriate reactions	500. relate to famous people	566. harmless
432. inconsiderate	501. reliable	567. her way or no way
433. insensitive	502. repetitive	568. he's difficult to talk to
434. interests / fascinations	503. reserved	569. unaware of danger
435. adult pornographic videos	504. resist change	570. underdeveloped social skills
436. boxing	505. respond out of proportion	571. unintentional
437. Chinese chess	506. rigidity	572. unpredictable
438. Hitler	507. ritual	573. unsociable
439. martial arts	508. routines	574. unstable emotionally
440. memorising football facts	509. rude	575. unusual
441. reading car manuals	510. rule bound	576. verbally offensive
442. rock n roll	511. selfish behaviour	577. volatile
443. star trek	512. semi-independent	578. vulnerable
444. steam trains	513. sensitive to loud noises	579. easily led
445. train spotting	514. sensitive to smells	580. not seeing consequences
446. train time-tables	515. single-minded behaviour	581. not seeing others' intentions
447. watching women wee	516. smashes things	582. socially unaware
448. Wednesday cake baking	517. social drinking to ease social awkwardness	583. walks strangely
449. interrupts people speaking	518. alcohol relieved anxiety	584. weird
450. isolated	519. calmest when drinking	585. withdrawn
451. just sat alone	520. drinking continued	586. wouldn't go on holiday alone
452. lethargic	521. feeling normal	587. wouldn't join in
453. like academic work	522. health costs of drinking	588. wouldn't mix
454. likeminded friendships	523. heavy drinking not part of new social scene	589. <u>How other respond</u>
455. loner	524. people noticed him	590. Negatively
456. loud	525. relations based on drink	591. abuse:
457. medication	526. social skills don't matter	592. bath incident
458. antidepressants helped at first	527. so depressed couldn't move	593. bullying
459. given countless pills	528. socially awkward	594. hair pulled
460. gained confidence on Prozac	529. socially inept	595. hitting
461. naïve	530. social phobia	596. laughed at
462. needing things just right	531. spent time alone	597. name calling
463. nervous nightmare	532. spontaneous impulses	598. spitting
464. never has a day off sick	533. stands out	599. teasing
465. no close friendships	534. strange	600. emotional
466. no close relationships	535. strange play	601. physical
467. not fitting in	536. stagmentation	602. rights
468. not what he wanted to do	537. stand and stare	603. sexual
469. no friends	538. stayed in bed for a week	604. accusatory
470. no social life	539. sticking out in a crowd	605. avoidance
471. non-conforming	540. stuck	606. bad treatment
472. not asking	541. geographically radius	607. blame
473. not belonging	542. housebound	608. confused
474. not normal	543. in childhood	609. couldn't really help
475. non-obvious eccentricities	544. mentally/emotionally	610. deny help
476. not recognising danger signals	545. unable to move on	611. difficult to understand
477. not very inhibited	546. stuck between two lives	612. dislike
478. obsessive	547. suicidal	613. dismiss problems
479. OCD	548. sulks	614. do not believe
480. odd gestures	549. take more than give	615. do not see AS
481. odd movements	550. threatening	616. do not see difficulties
482. one-track	551. timid	617. do not understand
483. outbursts	552. tired to develop socially – not successful	618. exclude
484. over-talkative	553. turbulent life	619. expel from school
485. oversensitivity	554. unacceptable behaviour	620. expectations
486. panics easily		621. high
487. paranoia		622. low
488. paranoid:		623. exploitation
		624. fearful
		625. fight against
		626. force to conform
		627. forget the difficulties
		628. harassment

629. help people with disabilities	698. squash	765. didn't like being left
630. ignore	699. superficial friend	766. didn't play with others
631. inhibit potential	700. they couldn't really help	767. didn't know what to do
632. inappropriate medical treatments /drugs/ ECT/psychodynamic counselling	701. things were being said	768. didn't know what to play
633. intolerance	702. unable to understand	769. didn't want to communicate
634. judge unfairly	703. unaware professionals	770. friendly with black boys
635. judgmental	704. unequal friendships	771. frightened by puberty
636. knows nothing about AS	705. unhelpful	772. happy before school
637. label	706. unkind	773. I'd invite children over he'd ignore them
638. lack acceptance	707. unrealistic expectations	774. I felt ought to be playing
639. lack of services	708. unsupportive	775. make up fantastic games
640. lack insight	709. use	776. never a problem
641. lack knowledge	710. victimise	777. never invited to parties
642. lack skills	711. wanted 'simple job'	778. never slept
643. lack understanding	712. write-off	779. no pretend play
644. limiting	713. wrongly accuse	780. problems from the start
645. maltreatment	714. Positively	781. quiet child
646. minimise problems	715. acceptance	782. sit and rock
647. mistaken impression	716. advising	783. talked and talked
648. misunderstand	717. advocacy	784. too scared to talk
649. negative labelling	718. assessments	785. very clever
650. aggressive	719. being nice	786. tell the time by 3 read by 4 yrs old
651. bad	720. believing	787. can hold a grudge for years
652. disobedient	721. come alongside	788. college isn't the right environment
653. disturbed	722. diagnosis	789. coped with an awful lot
654. freak	723. educational support	790. couldn't trust him around the baby
655. geek	724. fight for recognition/help	791. dislikes public transport
656. lazy	725. getting to know	792. doesn't like crowded places
657. naughty	726. giving time	793. doesn't mean to be hurtful
658. lout	727. identifies problem	794. everybody is different
659. mad	728. inclusive	795. focus on small things
660. shy	729. informing	796. forgetful
661. spoiled	730. listening	797. friends shared interest
662. thick	731. looking into it	798. goes on and on
663. no help	732. make a difference	799. he's the only one
664. no sibling support	733. making an effort	800. he has to make himself
665. nobody cares	734. networking	801. horrible!
666. obstruct diagnosis	735. non-judgemental	802. 'I can't do things'
667. offended	736. tried to help	803. incapacitated
668. one sided relationships	737. remembering	804. I'm childlike
669. offended	738. statement of need	805. 'it's a shame your married'
670. ostracise	739. supported employment	806. 'it's always someone else's party'
671. people believed he's alcoholic	740. supportive	807. 'it's OK to have these difficulties'
672. people don't see he's harmless	741. thrown out	808. life not stimulating enough
673. perceive as crazy/mad/bad	742. tolerance	809. loves slapstick comedy
674. perceive him as fairly able	743. try to help	810. made friends
675. perplexed	744. understanding	811. mercilessly bullied
676. pick on	745. very nice man	812. others getting married big problem
677. police/courts do not understand	746. willing to give a chance	813. needs the route mapped out
678. put down	747. Misc - young adults	814. needs support to move away
679. psychiatrists didn't accept AS	748. a gentle soul	815. never appreciates others viewpoint
680. puzzled	749. absent minded	816. never forgets events
681. quite good friend	750. accomplishments	817. never satisfied
682. refusing to help	751. a lot of failing	818. no imagination
683. reject	752. a lot of incidents	819. not appreciative of presents
684. sacked	753. alcohol v's AS	820. not quite the same
685. scared	754. asked her to marry me	821. not quite different
686. 'she was nasty'	755. can't cope with mothers new relationship	822. not ready to move on yet
687. shun	756. childhood:	823. peculiar child
688. see outward appearance	757. always on his own	824. picked on at school
689. send away	758. always running off	825. problems at home because of me
690. sensitive	759. always bit behind	826. relates to young children
691. scepticism	760. bullied by teachers	827. school a social jungle
692. social contact	761. clingy	828. sensory overload
693. wanting social contact	762. couldn't comfort	
694. not wanting social contact	763. cried all the time	
695. social skills don't matter	764. didn't know how to play	
696. society isn't tolerant		
697. spoke to me as a human being		

829. sickly	888. misdiagnosis	960. too late
830. significant contribution	889. mother arranged private	961. understanding
831. so innocent	890. rejects help	
832. some good times	891. self recognition of AS	6.8 Parent codes
833. space monkey	892. self-diagnosis	962. Parent experiences
834. talked often about life story	893. semi-independent	963. <u>Still being a parent</u>
835. time to think about being different	894. 'that's me'	964. a way of life
836. tries so hard tunnel vision	895. unaware	965. atypical
837. psychiatric hospital	896. unrealistic expectations	966. blamed
838. unable to problem solve	897. useful	967. continuous
839. verbal attacks only vicious circle	898. unusual IQ	968. dependent adult child dilemmas
840. washed out	899. 'we didn't know'	969. encompassing this way of life
841. went to university	900. Diagnosis - parents	970. knowing something wrong hard to know what's best
842. wrong end of the stick	901. acceptance	971. hard work
843. 'you seem nice'	902. access to clinicians	972. hidden role
	903. access to diagnosis	973. holding on versus letting go:
844. <u>Diagnosis of AS</u>	904. access to services post diagnosis	974. how will he cope
845. Diagnosis - young adults	905. a battle	975. no support
846. acceptance	906. advocacy	976. scared
847. ambiguity	907. bypassing the system	977. unable
848. affliction	908. clouded by ignorance	978. unwilling
849. as an adult	909. conflict	979. who else to pick up pieces
850. barriers to	910. diagnostic maze	980. who else will help
851. hard to accept anything wrong	911. early signs	981. 'how much is O.K?'
852. general lack of awareness	912. earlier would be better	982. intimate knowledge of needs
853. misbelieve	913. exacerbate problems	983. lack of awareness in others
854. professional unwilling to explore	914. expert diagnosis	984. long way to go
855. brings understanding	915. fobbed off	985. moulding self/lives around
856. denial of	916. fought for	986. no one to turn to
857. disclosing to others	917. great help	987. 'nobody else will do it'
858. displaced blame	918. helps:	988. non-obvious role/tasks
859. discovery of Asperger's	919. financial benefits (DLA)	989. not heard
860. doesn't quite fit	920. parents understanding	990. not listened to
861. don't need psychiatric label	921. others understand (lay and professionals)	991. not quite fitting in
862. don't think about it	922. requesting services	992. obligations
863. embarrassing	923. increasing general awareness	993. parent carer
864. exposing	924. knew for a long time	994. parent response
865. expert diagnosis	925. journey to recognition	995. active acceptance
866. diagnosed by Amita Shah	926. lack of resources even with diagnosis	996. passive acceptance
867. diagnosed by Digby Tantum	927. making excuses for behaviour	997. reluctant acceptance
868. diagnosed by Lorna Wing	928. my mother died not knowing	998. rejection
869. diagnosed by Pat Howlin	929. negates negative labelling	999. parenting an adult
870. diagnosed by Tim Williams	930. no benefit	1000. ongoing
871. fits all the categories	931. 'nobody understood Asperger's'	1001. powerless
872. felt better when diagnosed	932. normality	1002. never-ending
873. happy when AS diagnosed	933. narrow boundaries of normality	1003. not quite fitting normal
874. indifferent	934. widen boundaries of difference	parent role
875. informs	935. not a fad diagnosis	1004. relentless
876. it's a way of life	936. not detrimental	1005. selfless
877. legitimised problems	937. normalising versus differentiation	1006. still not on his own two feet
878. made sense	938. not wanting to stigmatise	1007. still very much the three
879. makes no difference	939. only time received help	1008. try to help
880. too late assessment	940. others awareness	1009. unable to find self
881. mother saw programme	941. others expectations	1010. unacknowledged role
882. not told	942. positive advances	1011. unheard voices
883. only mild	943. pre and post diagnosis	1012. unnatural
884. opens doors	944. private assessment	1013. unsupported
885. relief	945. relief	1014. untraditional
886. reject label	946. so many professionals missed	1015. <u>The things parents do</u>
887. rejection of social phobia diagnosis	947. sought out	1016. adapting personal/family
	948. stigma	1017. ambitions
	949. short fuse	1018. lifestyle
	950. suspicious	1019. routine
	951. take blame away from parent	1020. work
	952. use of services	1021. affection and love
	953. validates concerns	1022. aiming for 'successful different'
	954. valued	1023. anticipating
	955. wanting him to integrate	1024. arranging activities
	956. wanting others to understand	1025. educational courses
	957. wary of increasing feelings of being different	
	958. we didn't know what it was	
	959. welcomed	

1026. social engagements	1089. hygiene	1154. can't stand much more
1027. atypical	1090. nutrition	1155. completely broken down
1028. attending to needs	1091. positive attitude	1156. cumulative effect
1029. being available	1092. recognising when ill	1157. enjoy selves at another level
1030. build his confidence	1093. socialising	1158. dependent adult
1031. care	1094. supervising medication	1159. depression
1032. care without permission	1095. taking to doctor	1160. desperate
1033. checking	1096. managing	1161. don't feel I should have to do this anymore
1034. comfort	1097. change	1162. doubt
1035. companionship	1098. daily lives	1163. drained
1036. complexity of caring	1099. difficulties	1164. emotionally
1037. confidence building	1100. motivated for their children	1165. mentally
1038. covert caring	1101. motivation	1166. physically
1039. deliberate	1102. opportunities for developing	1167. 'drains me completely'
1040. inadvertent	1103. educationally	1168. driving me crazy
1041. creating opportunities	1104. personally	1169. duty
1042. for achievements	1105. socially	1170. effects everybody in the family
1043. for employment	1106. opportunities for mixing	1171. emotionally hard work
1044. for friendships	1107. opportunities for successful achievements	1172. exhaustion
1045. for social contacts	1108. persuade or trick	1173. exist day to day
1046. difficult situations	1109. planning and organising	1174. few rewards
1047. difficult to describe	1110. practical help	1175. family discord
1048. enabling	1111. cleaning	1176. family isolation
1049. fulfilling life	1112. cooking	1177. family tension
1050. safety	1113. food shopping	1178. fatigue
1051. emotional support	1114. housekeeping	1179. fear for his life
1052. encompass	1115. money	1180. gives nothing back
difficulties	1116. prompting	1181. guilt
1053. encouragement	1117. making choices	1182. helplessness
1054. everything has to be managed	1118. money/bills	1183. he's obsessive about me
1055. extraordinary lengths	1119. requests help	1184. home life is very difficult
1056. fight for provision of services	1120. travel	1185. 'I can't reach him'
1057. fighting for needs	1121. washing clothes	1186. 'I can't stand much more'
1058. financial decisions	1122. pre-empt potential problems	1187. 'I love him but can't go on'
1059. financial support	1123. protecting	1188. 'I'm very angry'
1060. future plans	1124. providing a feeling of 'belonging'	1189. ill health
1061. give more than take	1125. providing security	1190. I'm scared of him
1062. guidance	1126. providing structure	1191. impact on family
1063. hands off approach	1127. psychological watching-over	1192. inhibits
1064. hard to live with	1128. pushing him	1193. cannot move house
1065. help him feel normal	1129. recognising needs	1194. family events
1066. help him to be more	1130. responsible for	1195. holidays difficult
social	1131. safety-guards	1196. parent employment
1067. to have a better	1132. second guessing	1197. parent relationships
social life	1133. sharing of selves	1198. hard to be positive
1068. help move on	1134. social	1199. I have to be brave
1069. top be more	1135. social networking	1200. isolation
independent of me	1136. social skills teacher	1201. 'only stoic friends put up'
1070. help take risks	1137. staying with	1202. letting go of personal ambitions/desires
1071. 'hold on to what they've got'	1138. structuring	1203. little reciprocation
1072. information source	1139. supervision	1204. 'he doesn't know'
1073. integrate into society	1140. survival strategies	1205. 'he resents us'
1074. liaising with	1141. teaching others	1206. 'its all about him'
professionals	1142. there's nothing (no support)	1207. 'no consideration for us'
1075. let them grow	1143. thinking ahead	1208. life-long support
1076. looking after	1144. unseen structures	1209. chronic
1077. looking ahead	1145. working tirelessly	1210. unending
1078. managing	1146. <u>Psychosocial cost and benefits</u>	1211. living on egg shells
1079. day-to-day	1147. costs	1212. letting go of personal needs
1080. emotions	1148. alone	1213. lonely
1081. finances	1149. anxiety	1214. loss of dreams
1082. health	1150. being judged	1215. loss of future grandchildren
1083. learning	1151. blamed as overprotective	1216. lost opportunities
opportunities	1152. blaming self	1217. lost relationships
1084. links with employer	1153. can't move on	1218. loss of self
1085. maintaining health		1219. loss of time for siblings
1086. emotional		1220. lots of difficulties
1087. going to the doctor		1221. mixed feelings
1088. fulfilment		1222. marital breakdown
		1223. mental health

1224. affected	1279. humbled	1345. conflict: likes nest in tact
1225. moulding	1280. I'm proud of him	but knows he should go
1226. negative feelings	1281. involvement	1346. devastating effect on brother
1227. no breaks	1282. joining autistic society	1347. do the best we can do
1228. no help	1283. knowledge	1348. doesn't feel safe with father
1229. no privacy	1284. brings insight	1349. brother finds it difficult
1230. not natural	1285. new coping strategies	1350. can't risk making him worse
biologically	1286. is power	1351. didn't follow the rule book
1231. no understanding	1287. love to have him	1352. does that sound selfish?
1232. others	1288. learning from	1353. don't mind paying
misunderstanding	1289. meeting similar others	1354. don't want to make him iller
1233. overwhelming at	1290. no empty nest syndrome	family therapy
times	1291. not as badly of as others	1355. parenting course
1234. pain of child's pain	1292. pleasure	1356. services do not exist
1235. powerless	1293. purpose in life	1357. skilled help
1236. putting child's needs	1294. campaigning	1358. she was brilliant
first	1295. looking after	1359. slam doors in our faces
1237. putting life on hold	1296. supporting others	1360. unhelpful
1238. real battle	1297. respecting son/daughter	1361. unsupportive
1239. realistic expectations	1298. revaluing priorities	1362. unable to help
1240. regret	1299. sharing	1363. unwilling to help
1241. how we treated	1300. supporting others	1364. would like to do sociable
him	1301. unique perspective	1365. <u>Misc - parents</u>
1242. not understanding	1302. valuable life experience	1366. all my fault
1243. 'what might have	1303. valuing difference	1367. can't expect family to help
been'	1304. valuing life	1368. cope in spite of it not
1244. resentment	1305. valuing small achievements	because of it
1245. sad for him	1306. <u>Responses of others</u>	1369. It's not much of a life
1246. safety net	1307. a few supportive people	1370. impossible situation
1247. saps me dry	1308. accusations and blame:	1371. magic moment
1248. self-blame	1309. bad parent	1372. my heart sank
1249. selfish response	1310. bad parenting	1373. no faith in professionals
1250. shelter	1311. judgemental	1374. no measurable successes
1251. sick with stress	1312. inadequate parent	1375. nobody else allowed in
1252. small steps	1313. overprotective	1376. not fair on his sister
1253. so tired	1314. single parent syndrome	1377. 'one day he'll go one step
1254. stifles me	1315. accused of spoiling	too far for me'
1255. stressed	1316. bureaucratic	1378. one size doesn't fit all
1256. such a nightmare my	1317. confidentiality used as	1379. recognition for son with
mind has	excuse	Down's but not AS son
	1318. contribution not recognised	1380. small steps
	corporate dismissal of	1381. sister doesn't do much
	problems	1382. sister will take on care when
1257. takes of the self	1319. don't listen	we can't
1258. tied for life	1320. expect us to listen	1383. sister very good
1259. tiredness	1321. defensive	1384. sounds silly
1260. threatened me with a	1322. disinterested	1385. we are very lucky
knife	1323. excuses	1386. we can't go on
1261. total reliance	1324. experts	1387. couldn't past starting blocks
1262. unconditional	1325. he hit me with a poker	1388. family implications
presence	1326. he lives with me, not him	1389. happy if left alone in his
1263. understand	with	chair
1264. unhappy	me	1390. hasn't slept away from
1265. what will happen?	1327. is it right to label your son?	home
1266. who to turn to?	1328. labelling	1391. he can't do anything quietly
1267. worry	1329. inappropriate help	1392. he is suicidal
1268. present problems	1330. inconsistent	1393. he's the only one
1269. future - 'who will	1331. called upon in crisis	1394. hopeful
look	1332. not consulted to prevent	1395. hopeless
	crisis	1396. how long can you excuse
1270. benefits	1333. ignored	the behaviour?
1271. appreciate their	1334. my family blamed me	1397. how much is it OK?
special skills	1335. no solution	1398. I didn't know what to do
1272. becoming 'a better	1336. obstructive	1399. I'm going to cry
person'	1337. other son not coping	1400. I took the easy way
1273. campaigning for	1338. parents expected to rally	1401. what can we do?
others	1339. professional deafness	1402. worry he will hurt himself
1274. companionship	1340. professional incompetence	1403. worry he will hurt someone
1275. enjoying	1341. professional neglect	1404. would whack his brothers
son/daughter	1342. professional power	
1276. get on well	1343. recommending:	
1277. happy at home	1344. counselling	
1278. helping others		

Appendix 1e: Analytic memos

Category: Young adults: feelings Subcategory: Awareness

Codes: awareness the killer, something wrong, intangible, self-loathing, depression, alcohol & drugs as coping strategies

"... all I can reason is if people have it severely they don't realise there is a problem ... they are blissfully unaware but for us you realise there is something quite wrong ... something terribly wrong that you can't really put your finger on it you know and it's the awareness that's the killer I think ... I guess that's what causes the depression and self loathing, drugs, alcohol" [Ben. Interview 8: Para 50]

This participant perceived the awareness of being different from others, something being 'wrong', as making Asperger's syndrome more difficult to live with than those with classic autism who are 'blissfully unaware'. He highlights the intangible nature of Asperger's syndrome, 'can't put your finger on' i.e. *not quite fitting in*. 'It's the awareness that's the killer' – this is a powerful statement and conveys a sense of desperation, helplessness, and a damaged self-image (self-loathing). He also refers to coping mechanisms in drugs and alcohol used at first to ease the process of socialising and then becoming a source of physical dependence and poor health.

Note: Compare to William who also talks about awareness in remarkably similar terms. Also compare these interviews with others who appear less aware of their differences i.e. Dean and Robert. Does lack of awareness bring greater level of contentment and vice-versa? Could awareness also be related to level of integration or 'looking normal' i.e. hard to believe anything different about Ben and William from outward appearance or obvious behaviour, only when they tell their stories the Asperger's syndrome becomes more apparent. Thus greater self-awareness may lead to less awareness of their differences by others as they learn strategies to 'cover-up' or conform to others expectations.

Date last modified: 15/04/2005

Category: Young adults - Feelings Subcategory: Sense of self

Codes: solitude, personality suicide, social expectations, survival

"I am most content on my own ... I prefer being a solitude person ... that's fine with me ... A lot of people say to have a good time you go out and socialise right? Well for me that is a nightmare ... my good time ... to have a good time for me is to get away from that...to get away from that situation. I am totally the opposite ... it just puzzles me you know why they would want to do it. It is suicide...it is personality suicide. I need to survive" [William. Interview 5: Para 16]

This participant described his life in terms of 'survival', not just physical but personality survival. In this excerpt he talks about socialising as 'personality suicide' – he genuinely can't see the point of 'going out with others to have a good time'. To him it's the opposite; it's a 'nightmare'. He needs solitude to be himself. According to him to be with others is to kill his identity. This goes against theories of people as 'social beings' and our need for others to form and maintain our 'self' identities (see Mead, Goffman, Becker etc.). In the book 'Solitude' Storr (1988) challenges the widely held assumption that man is a social being who needs companionship and affection from other human beings from cradle to grave. Whilst the world tends to think of solitary people who do not share the pains and pleasures of the average person as peculiar odd human beings, Storr (1998) questions whether this difference from the average implies abnormality in the sense of psychopathy or a biologically adaptive deviance through which important contributions to human knowledge and understanding are gained?

Note: Consider positive aspects of solitude. Don't force own assumptions onto how others should be, or how they define themselves. Think about how this might fit (or not) with theories of self, and the development of identity? How far do other participants subscribe to William's view of solitude? Others such as Sebastian appear to crave company.

Date last modified: 12/05/2004

Category: Parents Subcategory: Costs/ Emotions

Codes: mixed feelings, sad for him, empty nest syndrome, positive feelings, love him here, part of the family, selfish response,

"...it is sad for him [...] I think empty nest syndrome is always a problem as your children grow older they go away and lead their own lives and so that the mother and perhaps the father to a lesser extent is sad then ... I don't have an empty nest ... I still have Carl very much in the nest and for me personally it's not sad because I love to have him still as part of the family but that is a very selfish response [Carol. Interview 3 Para 7]

This mother was saying that she loved having her son as part of the family although she was sad for him, but not so much for her. She enjoyed his company. He was a focus for her in her life and still part of the family. She discussed 'empty-nest syndrome', when adult children leave parents behind and parents feel sad at this loss, but she hasn't had to face this with her son. She saw this as a selfish response and when on the express her preference that he was doing the 'natural biological thing' in leaving home and forming his own family. Thus she has mixed feelings. However, she was very positive about her son and their situation, more so than other parents interviewed.

Note: Compare with others who are less positive about their son or daughter still living at home.

Date last modified: 08/10/2005

Category: Parents Subcategory: Costs / Emotions

Codes: guilt, duty, obligation, tired, mixed feelings, can't stand much more, negative feelings

"As mind and body and soul can take, he pushes you to the limit and you feel so tired, you just want to walk away and then you think don't be silly he's your son but then you think 'I don't want him to be here, I can't stand much more of this" [Jill. Interview 27 Para 22]

This mother's situation seems all consuming 'mind, body and soul'. Her son 'pushes' her to the 'limit' – what stops her from going over the limit (throwing him out, walking away)? – Duty and guilt – he is her son (parental obligation). 'Don't be silly – what is silly about it? Societies expectations of family obligations or a reflection of her view of herself – she takes the blame for not being able to cope. Yet she also talks about him all give and no take [Link to G.H. Mead's I and me selves] so is her predicament something to do with the non-reciprocal relationship between parent and son.

Note: Some parents (i.e. Carol) seem able to positively encompass their son or daughter within their lives and others seem to struggle. Likely to do with psychological and social resources for living in both parent and young adult (see Antonovsky) Could be the subject of further study.

Date last modified: 21/10/2005

Appendix 2a: Participant profile

Young adults pseudonyms	Age at interview	Age of diagnosis	Young adult interviewed	Parents interviewed	Parents pseudonyms
1. William	19	21	Yes	Yes	Sarah
2. Carl	26	n/a	No	Yes	Carol
3. Ben	27	26	Yes	No	
4. Nick	23	14	Yes	No	
5. Richard	29	20	Yes	Yes	Mark & Jane
6. Philip	35	33	Yes	Yes	John & Mary
7. Kate	31	25	Yes	No	
8. Tim	26	24	No	Yes	Peter & Fran
9. Robert	35	32	No	Yes	Marie
10. Sebastian	28	12	Yes	No	
11. Andrew	34	31	Yes	Yes	Diane
12. Thomas	28	26	Yes	No	
13. Lisa	22	15	Yes	Yes	Roger & Sue
14. Rachel	31	27	Yes	No	
15. Matthew	23	18	Yes	Yes	Sandra
16. Dean	32	29	Yes	Yes	
17. Daniel	22	16	Yes	Yes	Judy
18. Guy	29	25	Yes	No	Alex & Ann
19. Luke	24	18	No	Yes	David
20. Glen	32	27	No	Yes	Margaret
21. Jack	28	23	No	Yes	Jenny
22. Martin	21	15	Yes	Yes	Jill
23. Paul	23	19	No	Yes	Amanda
24. Naomi	27	25	Yes	Yes	Julie
25. James	20	17	No	Yes	Claire

Appendix 2b: Interview profile

Number of families	25
Number of participants	41
Number of young adults	18
Sets of parents	18
Mothers	17
Fathers	6
Total parents	23
Primary Interviews (face-to-face)	36
Young adults alone	12
Parents alone	12
Young adult and parent/s simultaneously	6
Repeat Interviews (face-to-face)	6
Young adults	3
Parents	3
Follow up telephone interviews	8
Young adults	3
Parents	5
TOTAL INTERVIEWS	50
Face-to-face	42
Telephone	8

Appendix 3a: Sample letter to potential participants accompanying information sheet

Date ...

«Title»«FirstName»«LastName»

«Address»

«Postcode»

Dear «Title»«FirstName»«LastName»

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the information sheet carefully and discuss it with friends, relatives and your GP if you wish. Please ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part

Many thanks

Yours sincerely,

Suzy Portway

PhD student

Contact details: ...

Appendix 3b: Information sheet for potential participants

INFORMATION SHEET

Title of project: Living with Asperger's syndrome

Explanation: The research is being carried out as part of a PhD study within the Department of Nursing Studies, King's College, London

Researcher: Suzy Portway BSc (Hons) RGN RHV DN

Contact details:

Supervisor: Dr Barbara Johnson PhD RGN RHV QN Tech. Teachers Cert.

Contact details:

The purpose of this research is to gain insight into the lives and experiences of young adults with Asperger's syndrome and their parents.

You have been chosen as somebody who may be able to contribute to this research. If you agree to participate, Suzy Portway would contact you to arrange a mutually agreeable place to meet for an interview. This could be at your home or at the ... office at ... If you would prefer to meet somewhere else, alternative arrangements can be made.

Interviews vary in length of time but are anticipated to last between 1-2 hours. It may be useful for more than one meeting, although you would be under no obligation to meet more than once. With your consent the interview would be audio-taped. You would be asked to talk through your life story and experiences that you feel would be helpful to the purpose of the research.

All information you gave would be treated as confidential and remain anonymous. Nobody but the researcher and supervisor would have access to your personal details, the audio recording and notes. All names would be changed and notes / information would be stored on a security locked computer and/or a locked cabinet. No real names would be mentioned in any writings, reports or presentations, although anything that you said during the interview could be used, anonymously, in the presentation of the research. Audio-tapes would be destroyed on final completion of the study. No names and addresses would be passed onto anyone else. It is up to you whether or not you decide to take part. If you do agree to participate you would be asked to sign a consent form, however, you would be free to withdraw from the study at any time and without reason. This would not affect the standard of care or services you receive.

King's College, University of London, Research Ethics Committee has approved the proposed study and the above statement.

Thank you for taking time to read this

Appendix 3c: Sample consent form

PARTICIPANT CONSENT FORM

Title of project: Living with Asperger’s syndrome

Name of Researcher: Suzy Portway

Contact details

Please initial each box

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions

☐
2. I understand that my participation is voluntary and that I am free to withdraw any time, without giving any reason, without my care or legal rights being affected

☐
3. I agree to take part in the above study

☐
4. I agree that any words I may say during the interview can be used, anonymously, in the presentation of the research

☐

<div>Name of participant</div>	<div>date</div>	<div>signature</div>
<div>Researcher</div>	<div>date</div>	<div>signature</div>

**King's College London
Research Ethics Committee**

c/o Department of Nutrition,
King's College London,
150 Stamford Street,
London, SW1 8WA.

Telephone: +44 171 848 4613 (direct), +44 171 848 4268 (dept office).

Facsimile: +44 171 848 4613 (secure),

e-mail: ethics@kcl.ac.uk

plst

Ms Sue Portway,
19 Cawsam Gardens,
Caversham,
Reading,
RG4 5JE.

Fax to: 0118 958 6022

21st March 2000

Dear Ms Portway,

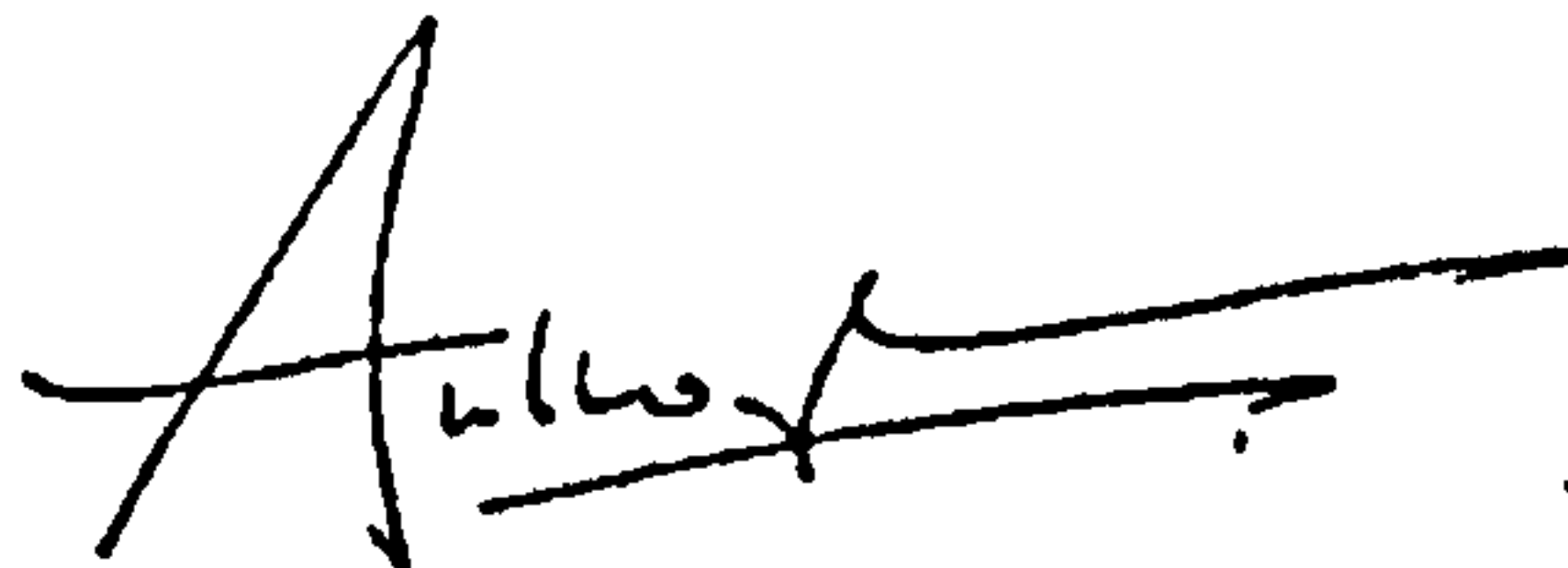
Re: 99/00-38 The community health needs of socially vulnerable adults and their families. Barbara Johnson, Sue Portway, Nursing and Midwifery.

Thank you for your application which was presented to the Research Ethics Committee at its meeting held on March 1st 2000.

I am pleased to tell you that the College committee has now approved the application. Members of the committee recommended that in the interests of your own safety the interviews be done in the offices you described, or if home visits are necessary then they recommend that you be accompanied. As with all recorded interviews the committee expects the audio recordings to be erased when you have finally analysed the data (reference to this should be on the information sheet). The committee also recommended that you ensure that you have adequate contacts with Social Services in case you need to use that network should you detect some issue which merits help.

I apologise for the delay in processing this application, and wish you success with your work.

Yours Sincerely,



Anthony R Leeds
Chairman,
Research Ethics Committee.

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